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ABSTRACT

The report describes a regionalized system of community based child health centers developed in Iowa to provide coordinated secondary level health services for children with chronic illness and handicapping conditions. The system is based on two principles: (1) Communities will be given the responsibility for determining which health services are needed and for providing these child health services with state programs serving as the backup resource; (2) Community programs that provide child health services will function in close cooperation and collaboration with established community systems (medical care system, educational system and social services system) that provide other child services. Chapters of the report have the following titles: (1) Introduction; (2) Networking to Achieve Change; (3) Development of Regional Center Service System; (4) A Stratified System of Care; (5) Results: The Creation of a System of Services; (6) Data, Interpretation, and Evaluation; (7) Lessons and Conclusions; and (8) Future Directions, Questions and Issues. A 34-item bibliography is followed by an appendix containing such items as the inter-agency memorandum of understanding, an individual service plan summary, a health survey report, health services questionnaires, and evaluation data. (Author/DB)

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Networking through Regional Child Health Centers:

An Alternative Delivery System

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Networking through Regional Child Health Centers: An Alternative Delivery System

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November 1986

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GLOSSARY

AEA	Area Education Agency
BCHS	Bureau of Community Health Services
CCS	Crippled Children's Services
CHSC	Child Health Specialty Clinics (formerly State Services for Crippled Children)
DHS	Iowa Department of Human Services (formerly Department of Social Services)
DOE	Iowa Department of Education (formerly Department of Public Instruction)
DPH	Iowa Department of Public Health
DPI	Iowa Department of Public Instruction
ENT	Ear, Nose and Throat Clinics at Selected Regional Centers
FY	Fiscal Year
IAPT	Information for Assessment, Planning and Tracking
IEP	Integrated Evaluation Plan
IEPC	Integrated Evaluation and Planning Clinics
MCH	Maternal and Child Health Services
NICU	Neonatal Intensive Care Unit
OSERS	U.S. Office of Special Education and Rehabilitation Services (formerly BEH--Bureau for the Educationally Handicapped)
P.L. 94-142	Education for all Handicapped Children Act
PNP	Pediatric Nurse Practitioner
RUSP	Residential Unit Service Program
SSCC	Iowa State Services for Crippled Children
Title XIX	Medicaid
UIHC	University of Iowa Hospitals and Clinics
WIC	Women, Infants and Children Program

Acknowledgements

Many persons, agencies, programs and community organizations have helped to make the regional center system in Iowa a reality during the last decade.

This report about the development of the regional center system is prepared with special recognition for the support, encouragement and interest of Merle McPherson, M.D., Chief, Habilitative Services, Division of Maternal and Child Health, Department of Health and Human Services, Rockville, MD; with special appreciation to the members--past and present--of the regional center boards; to the regional child health center staff and to the contributions of persons from many state agencies and local programs and organizations. We note with special thanks the skilled typing of Kathy Breese, CHSC, for the many drafts of this report and to Lynne Cannon, Ph.D., for her skill in editing and clarifying that which we wanted to express.

I. Introduction

Services for children—putting the pieces together

MENTAL RETARDATION

HYPERACTIVITY (A.D.D.)

SERIOUS EMOTIONAL DISTURBANCE

BEHAVIOR PROBLEMS

SPEECH PROBLEMS

HEALTH PROBLEMS

VISUAL HANDICAPS

HEARING IMPAIRMENT

IMPAIRED MOBILITY

SPECIFIC LEARNING DISABILITY

It's a puzzle.

General Overview

This report describes a regionalized system of community based child health centers that have been developed in Iowa to provide coordinated secondary level health services for children with chronic illness and handicapping conditions.

We are in a time of change in the American system that provides services for children who have chronic illness and/or handicapping conditions and that, during this transitional period, strong forces are vying to determine what the new system should be.

There is a "new morbidity" that is only partially recognized by those who are trained to provide services for children with traditionally recognized health problems, so there is a need to redefine the population in need of services to include children with a variety of health and health-related problems.

The traditional mobile clinic program used by this and other state crippled children's programs is not adequate and cannot provide the services needed by children included in a modern definition of children in need of specialized health services.

There is a need to develop a new system to provide the services needed by these children.

Just as we must have a three-tiered system of health services for children with acute disease if the children are to receive comprehensive services, so we must have a new three-tiered system of health services for children with chronic illness and handicapping conditions if they are to receive comprehensive services.

-- The tertiary level services for these children are well organized in medical centers and these centers will continue to provide a major part of the specialized diagnostic-treatment services needed by this population of children.

-- There is a need to develop a new secondary level of services for these children.

-- The primary medical services for these children should be strengthened by educating primary care physicians about the ongoing primary medical services needed by these children.

To propose that there is a need to develop a new system to provide a secondary level of care for children with chronic illness and/or handicapping conditions initiates a major controversy. Is such a change needed? How and where should services be provided? Who should be responsible for designing--for conducting--the system? The parties involved in the controversy have strong opinions about these matters because their professional and financial interests are at stake.

It is not difficult to make the case for the need of a new system to provide Level II services for children who have chronic illnesses and/or handicapping conditions.

There is, therefore, a need to create at the community level a service unit that will allow and encourage the cooperative professional effort needed to make health-related services accessible to all children.

There is a need for bold planning to design a new system that will insure that all children have access to the health services that are unique to children: basic health services; health services for chronic diseases and disorders; and health-related services.

Among the principles of the new system, two stand out:

1. Communities will be given the responsibility for determining which child health services are needed and for providing these child health services with state programs serving as a backup resource.

2. Community programs that provide child health services will function in close cooperation and collaboration with established community systems (medical care system, educational system and social services system) that provide other child services.

The Regional Child Health Centers described in this report are viable options for communities and states to consider to meet the special needs of handicapped children and those with chronic disease. This system was developed to be compatible with other health care systems and so no issue is made on the design of the clinics in this system or their operating procedures. We recognize that networking does not occur spontaneously nor can it be carried out around the individual problems of each child. Networking requires a framework--some degree of organization and some establishment of agreement between the parties providing the services. One of the major accomplishments of the development of child health centers is to provide the framework which is needed if networking and coordination of services is to occur.

II. Networking to Achieve Change

A Letter From A Parent

Networking of services always involves people. When all else is said and done, no system however well-designed and no services however skillfully delivered are of any value except to the children and their families who are in need of them.

"Dear.......

We have recently been through the clinic in Waterloo with our adopted daughter, Marcia. She is from Viet Nam and is suffering from inadequate care, pre- and postnatal. We have explored many avenues to figure out why she learns so erratically. At this clinic they suggested that we try the drug, Ritalin. The difference is a marvel! She can now pay attention in school, listen and follow directions. We are delighted!

Many of the children have so much more serious problems than Marcia. I hate to think that the (funding) cuts we make might be those that effect our children. Lets cut in other areas first and keep programs for our kids as long as possible.

I know that in a family when things get tough, we cut back. But we cut back with a plan. First we cut out the frivolous, lovely earrings or that handsome gun case. Next the things we like but don't have to have, new furniture. We can cut back further, read magazines from the library and stop buying prepared foods. I'm sure I could go on and on, but only when things get really bad do we really cut back on the kids. As long as we can we see that they get the proper food, proper health care, the things they need to grow up strong and healthy. If one child has special needs, we see to that.

Sincerely yours

Mrs. ...."

Networking

Networking through Regional Child Health Centers: An Alternative Delivery System documents the coordinated efforts of the Iowa Mobile and Regional Child Health Specialty Clinics (CHSC) and education agencies, human services, and public health services to create a secondary level service system to serve children who are physically disabled, educationally handicapped or those with chronic disease.

The need for a network of coordinated and secondary level services for the handicapped has now been extensively documented (see Bibliography). Studies have noted the development of massive federal and state programs with large budgets and the federal and state mandates to serve the same or similar populations of children. Problems are compounded by conflicting state and federal statutes and regulations which restrict access to service and by various types of categorical and functional eligibility requirements. Economic conditions and public attitudes toward human service programs will no longer tolerate the lack of coordination among services, uneven distribution of services, and a piecemeal approach to providing services.

In the last few years, the concept of "networking" has developed. Previously the focus was on "integration," "coordination," and "coalition building." These are similar concepts with shifts in emphasis.

Networking is defined as:

> A fabric or structure of cords or wires that cross at regular intervals and are knotted or secured at the crossings; a system of lines or channels resembling a network; an inter-connected or interrelated chain, group, or system; a group of radio or television stations linked by wire or radio relay; and, a radio or television company that produces programs for broadcast over such a network.

The key words in the definition are: structure, system, interrelated chain or group, and linkage. The focus is on tying together various components into a system--an interrelated system, in which each piece retains its own identity but functions as part of the whole; and, the sum of the whole is greater than its individual parts.

The question is, "Even though networking is desirable, is it possible?" What are the various problems related to shared responsibilities, issues of confidentiality, agency guidelines, eligibility requirements and reimbursements? In a well-known study on the coordination of services, Jerry O. Elder and Phyllis R. Magrab, make this observation,

> "there is a natural tendency for agencies to avoid creating interdependencies except in relatively safe areas that are auxiliary to the main organizational objective. However, this is not seen as a deterrent to developing interagency collaboration. If anything, this tendency fosters interagency working relationships. An educational agency is more likely to enter into a joint program with agencies and other service delivery areas to provide, for example, health or social services than it would be to develop a joint program with another educational agency."

Child Health Specialty Clinics has developed a network of 12 regional child health centers to provide a secondary level of care for children with handicapping conditions and/or chronic disease or illness with various types of services. We believe these regional centers are a viable option for communities and states to meet the special needs of handicapped children and those with chronic disease. This report describes the experiences in the development and the operation of this new service system in the state of Iowa. The system of regional centers is now in place, and while still in various stages of development, the centers are successful and have a broad base of public support.

The centers and their clinics are not the only possible solution. However, the principles upon which the Iowa model is based deserve careful consideration by those responsible for providing team care to handicapped children in their home communities or neighborhoods.

Jerry O. Elder and Phyllis R. Magrab, (Ed). Coordinating Services to Handicapped Children: A Handbook for Interagency Collaboration. Paul H. Brookes, 1980, p. 6.

Operation of the centers is detailed in a separate volume, "Community Child Health Centers: A Manual (SSCC 1979)," and in the individual operation and procedure manuals for each center available from CHSC offices, Iowa City, IA.

Background: A New Population of Children Requiring New Services

In 1975, Child Health Specialty Clinics (CHSC--formerly Iowa State Services for Crippled Children) undertook to design a comprehensive system for the care of a new population of children with handicapping conditions. The two important concepts are: comprehensive system--and new population of children.

The need for a comprehensive system can be understood from a brief discussion of the development of child health services in this nation and the need to develop new services for a new population of children with actual or suspected, acute or chronic, congenital or acquired, disorders and diseases.

Major changes have occurred in the field of child health care in the 20th century. These changes affect physicians, nurses, those in special education, social workers, and support personnel. Further, the changes affect not only the professional disciplines but the system through which the services are provided.

At the beginning of the 20th century, the majority of services for children were provided by the family physician during office visits, at home, or in a local community hospital. Professional health services focused on the treatment of common children's problems: diarrhea, diphtheria, polio, meningitis, infections, pneumonia, and emergency care for acute injuries and accidents.

By the 1950's, there were new services provided in physicians' offices which focused mainly on routine neonatal care. At the same time various childhood illnesses were being rapidly eradicated. Other problems of children such as "failure to thrive," central nervous system diseases, congenital heart disease and cystic fibrosis were being identified and treated in regional hospitals.

More major childhood diseases were eradicated or brought under control by the 1970's. The physician's office still remained the place of choice for treatment of acute medical problems. However, a small cluster of new services were provided in regional hospitals: high risk neonatal care, renal dialysis, treatment of childhood leukemia, and genetic diseases and counseling. Community health services were expanding to include treatment of chronic disease and supervision of developmental, behavior and learning problems.

Legislative Changes

In 1934, those who were responsible for developing the Title V amendments of the Social Security Act established the revolutionary idea that each state should have a unit of government that would be designated to be responsible for making high quality services available to the crippled children in the state. At that time, the major recognized problems that resulted in children being crippled were paralytic poliomyelitis, cerebral palsy, and various congenital orthopedic problems. These crippling conditions required specialized medical-orthopedic-surgical services so most states created a health care delivery system composed of regional clinics and staffed by medical specialists.

In the years that followed, the state CC programs came to recognize that since other medical diseases were crippling, they expanded their programs to provide services for children with a large number of chronic illnesses and handicapping conditions.

However, few state programs have seen fit to change the system to provide those services. Many of the diseases that have been identified in recent decades as the result of advances in biomedical research require services that cannot be provided in such a system.

Further, several major legislative acts were passed which provided parents and children with specific legal safeguards to insure their participation in or knowledge of programs and services. Of particular importance were P.L. 94-142, the Education of All Handicapped Children Act; Section 504 of the

Rehabilitation Act of 1973; and P.L. 95-602, the Developmental Disabilities Act. These legislative acts brought to the attention of public agencies a population of children with very different types of health and educational problems from those previously served. For example, the implementation of P.L. 94-142 and its "mainstreaming" and "least restrictive environment" concepts required public schools to provide services for all children whose educational experiences had been restricted or compromised by their handicaps. The result has been the identification of children with a wide variety of medical, developmental and behavioral problems. These children require different services than those provided in the earlier typical handicapped children's programs.

The New Morbidity

Service providers became aware of a large number of new children's problems, referred to as the "new morbidity," that can be handicapping and must be addressed.

This target population of children requires medical care from the health field, special education from public school systems, frequently assistance from the Department of Human Services and a variety of other community programs including support groups for parents.

It is now recognized that the treatment of various types of handicapping conditions and chronic diseases is complex, sophisticated and specialized. No longer can the family physician or any other single professional treat all handicaps individually. Modern treatment requires a professional team composed of many disciplines working in close harmony and mutually supporting the efforts of each other. Evaluation of handicapped children should be in a clinic setting with multiple examiners and formal or informal staffings to coordinate services provided by various agencies and multiple professional disciplines.

Handicapped children need comprehensive case planning adapted to each child's needs and to the community. Services to the individual child must be specified and responsibility for them assigned to the appropriate professional person(s) or agency(s).

Changes in the System

Because families of children who had these new forms of diseases had difficulty in obtaining services in the established system of care they banded together to enact categorical legislation to create special health service programs for children with these diseases and health problems.

The problem was further complicated by the passage in the 1960's of legislation providing new categorical child health programs to benefit unserved or underserved children. One study of federal programs by the United States Senate Committee on Finance identified 21 different programs that provided direct health care and 14 programs that provided support services for these children.

Each of the public programs providing health and health related services for handicapped and chronically ill children was created for good cause and deserves support. But, each of these programs was created without considering others that also provide services; each was organized to function independently of other programs and was not coordinated with them. As a result, each program developed its own constituency, operated on its own legislative mandate and had its own administration, regulations, staff and eligibility requirements. This left public programs for handicapped children fragmented and frequently resulted in duplication of service and cost. More important, it became increasingly difficult for parents to obtain services efficiently and effectively and frequently resulted in a lack of service because parents could neither comprehend the complex structure of the system nor compare the programs available.

A modest step was taken to correct this problem with the passage of the Maternal and Child Health (MCH) block grant legislation in 1981, but in fact an unbelievable degree of fragmentation of health services continues.

It should be noted that although there is the need to develop a network of services for children, there is not necessarily a need to develop a new super services organization. Rather, representatives of programs that currently provide services for handicapped and chronically ill children in the community must work together to provide a network of coordinated services. Coordination of services allows providers to retain their own roles as they work to develop a unified system of care.

New health services for recently recognized health problems were being developed in the 1970's and the 1980's. These services must be available for comprehensive care of handicapped children. Some of the new services provided for handicapped children include: (1) interdisciplinary services for children with health, educational, behavioral and developmental problems; (2) follow-up services for infants born at high risk; (3) services for the promotion, prevention and early identification of chronic illness and handicapping conditions; (4) services for handicapped adolescents; (5) services for ventilator-dependent and other technology-assisted children; (6) services for low incidence groups such as hemophilia, Prader-Willi syndrome children, etc.

The Iowa Chapter of the American Academy of Pediatrics reacted to the changes in this way: "The advent of the Education of the Handicapped Act and the Intermediate Care Facility/Mentally Retarded (ICF/MR) legislation brings new financial and support resources for handicapped children to Iowa communities, but the methods whereby physicians will provide medical services for these children have not been determined."

The Chapter noted that "there is a need for selected physicians to obtain further training in the provision of care for handicapped children so that they can work with other professionals to provide modern services for handicapped children." More importantly, the Chapter expressed "a need to create a system that will allow and encourage integration of medical, social, educational services so that a handicapped child can have a single program of service."

Thus, it has become apparent that major changes should be made in the current system that provide services for these children and it was this awareness that caused the CHSC to review its programs and services.

The Iowa Crippled Children's Program Responds

In the late 1960's, the Iowa Crippled Children's program had become aware that changes were occurring in the provision of services for children with chronic illness and handicapping conditions. This agency set about to identify the problems that existed and the solution to those problems. The first effort was a project in 1966 that was conducted in conjunction with the Iowa Department of Public Instruction in which all the children in a six county area in north central Iowa who had any form of handicapping condition or disability were given a comprehensive health education examination. The findings of that study were reported and resulted in a number of important conclusions. One of those was the need for a new definition of what constituted a handicapped child. Another finding was the difference of perception that existed between the state CC staff and the parents of the children as to what services the children needed. This difference was recognized when the list of services the examining staff felt the child should have was compared to the list of services the parents felt their children needed. To our surprise and embarassment, there was very little similarity in the two lists.

About this same time, the Iowa CC program conducted a series of "post clinic conferences." These were community staffing conferences that were held following a mobile field clinic. The community professionals who attended the conferences were involved with the care of the children attended and participated in the design of the recommendations and that program of care. Those conferences convinced the Iowa Crippled Children's staff that to develop a proposed plan of care without involving the persons in the community who were to carry out the program was fraught with the very real possibility of being off target and with developing inappropriate, if not impossible, recommendations.

The information gained by these two projects confirmed to the Iowa Crippled Children's service staff that it was important to consider a very new type of service program to provide new services to a new population of children. As the result of that conviction, the Iowa Crippled Children's service in 1976 developed the report, "The Provision of Contemporary Child Health Services in Child Health Centers." That report became the long term plan for the Iowa Crippled Children's service.

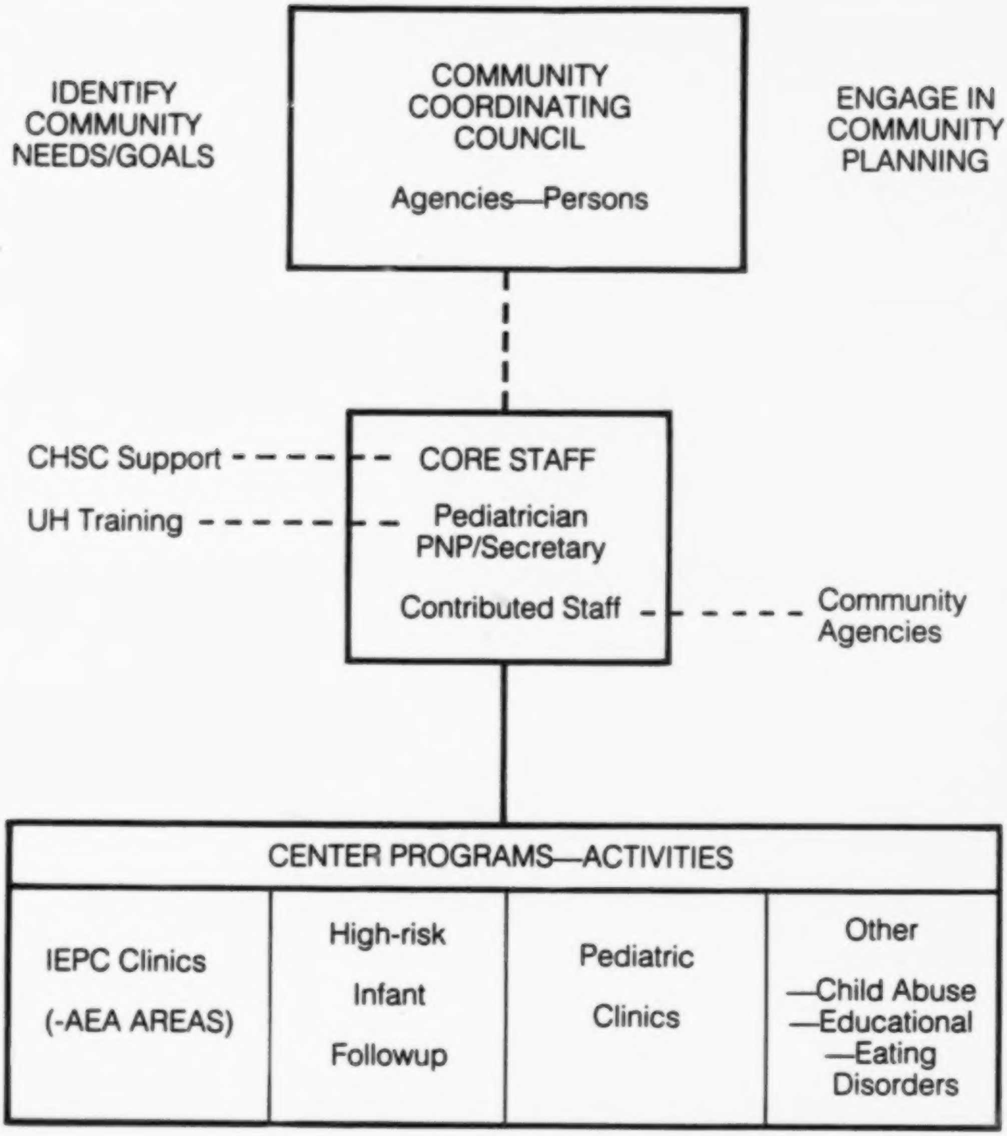
The first step in implementing the concepts included in the report was to create child health centers in two Iowa communities. At the end of two years, major changes in the design of the centers had been made. At that time, the Office of Maternal and Child Health and the U.S. Department of Education initiated a program to support demonstration programs for the purpose of exploring methods of cooperation between health and education agencies. The Iowa Crippled Children's program applied for and received one of those grants which allowed us to expand the centers into three new communities and to continue our demonstration service center project.

In 1981 on the basis of the progress made in the centers, the Joint House/ Senate Appropriations Subcommittee for Human Resources of the Iowa State Legislature charged the Iowa Crippled Children's Service, the Maternal and Child Health program, the Department of Public Instruction, and the Department of Human Services to conduct a year's study of the services available to mothers and children in the state. This study was completed and resulted in the "Green Book" report. The report was accepted by the committee and the programs involved were charged to continue coordination of services with special emphasis given to two model centers in Ottumwa and Sioux City, Iowa. At that time, the committee also appropriated state funds toward the support of a statewide regionalized system of community health centers.

The idea of funding demonstration projects has been a long and well-accepted policy of the federal government and in particular of the Office of Maternal and Child Health. In truth, the rate of success of such demonstration projects has not been as great as would have been liked. The idea was that if the project has merit, the state would provide funds to continue its operation. Many worthwhile projects have not failed because of their outcome, but because they were not brought to the attention of those responsible for state budgets or they came up for consideration at a time when state funds were not available. The success of the program described in this report was no doubt the convergence of a state appropriation committee interested in the idea of making state government work in a cooperative if not integrated manner.

III. The Development of the Regional Center Service System

The Regional Child Health Center


IDENTIFY COMMUNITY NEEDS/GOALS
COMMUNITY COORDINATING COUNCIL
Agencies—Persons
ENGAGE IN COMMUNITY PLANNING
CHSC Support
UH Training
CORE STAFF
Pediatrician
PNP/Secretary
Contributed Staff
Community Agencies
CENTER PROGRAMS—ACTIVITIES
IEPC Clinics
(-AEA AREAS)
High-risk
Infant
Followup
Pediatric
Clinics
Other
—Child Abuse
—Educational
—Eating Disorders

An Idea is Developed

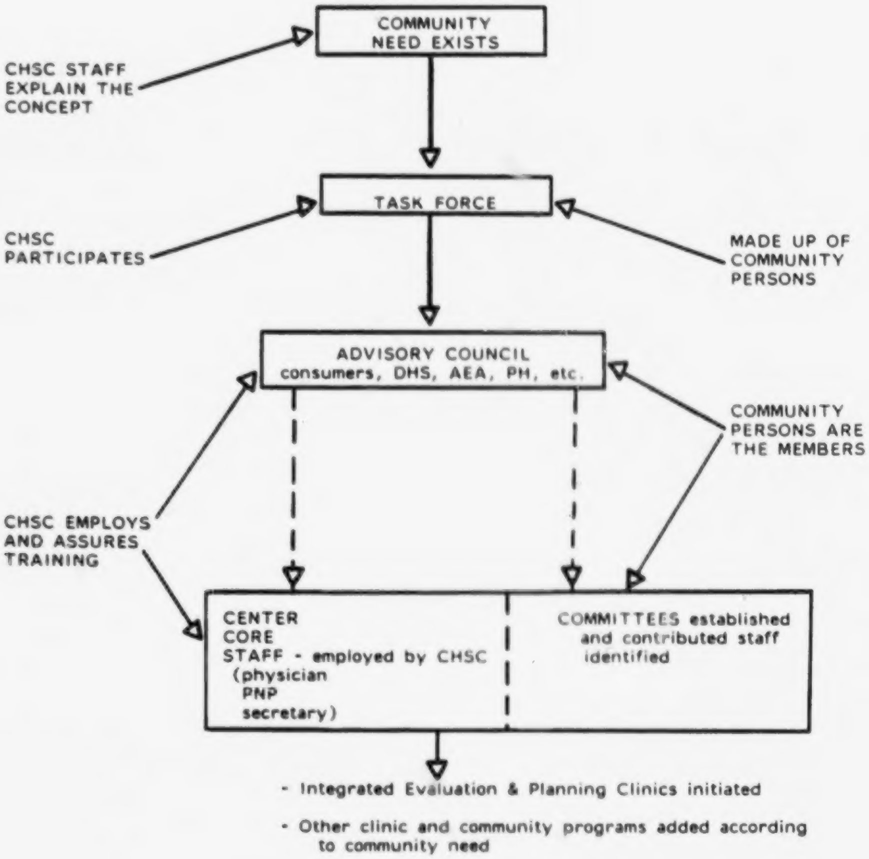
The Rand Corporation reported in 1973-1974 that the problem of providing comprehensive services to the handicapped child and his/her family was the clear identification to all parties involved of who is doing what and in what sequence. The report noted that it is not primarily a problem of funding, legislation, high quality service programs, professional staff or involved parents, but one of planning and organizing the service programs to meet the individual child's needs.

CHSC had become aware that: (a) an increasing number of children with complex health/education-related problems were being referred to the mobile field clinics of this agency. (b) These children required evaluation by professional teams on a multidisciplinary basis, individual case plans appropriate for the child and the communities in which each resided, and multidisciplinary services. The feasibility of community-based multidisciplinary teams of professionals to serve this population of children was considered. The agency tested different regional clinic models to determine how best a community team could provide services for children with various handicaps. These clinics would have to be adapted to a rural state with many low population areas and relatively few urban communities. For three years, several regional clinic models financially supported by CHSC were conducted and evaluated. This support represented a significant agency contribution and was extremely important to the development of a network of services.

In 1975 the agency employed a community-trained organizer to live in each of the four quadrants of the state and develop pilot community councils in the closest special education area. The Department of Social Services (now Department of Human Services) also had a regional planning system similar to the special education areas and cooperation with both of these agencies was essential.

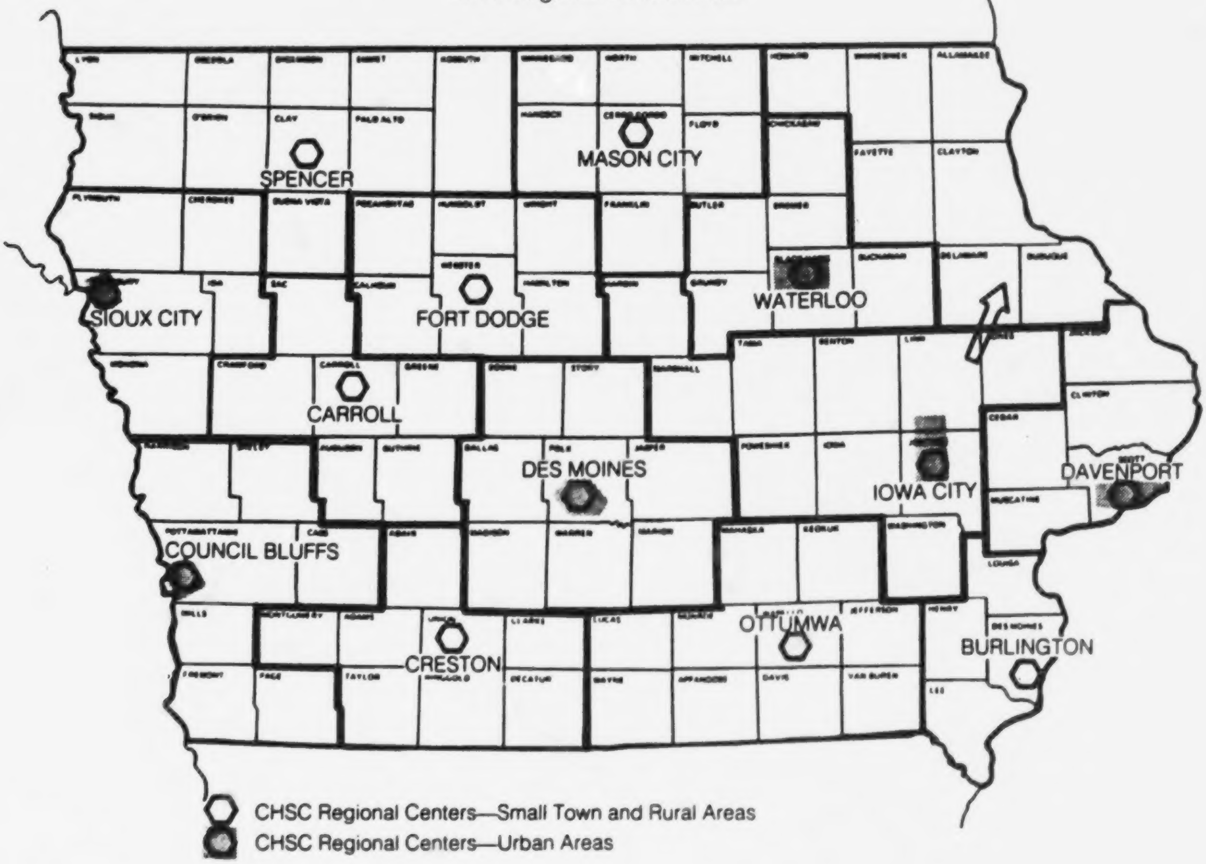
Each of the community organizers generated interest in the proposed new regional clinic system and organized a community board to assume responsibility for planning, developing and establishing operating policy for each regional clinic. As will be discussed in more detail later, the community organizers were very successful in establishing a nucleus of four regional centers. The organizers assisted these pilot community boards in such basic matters as incorporation and bylaws, the selection of sites for the centers and memoranda of understanding (see Appendix-I). As a result of considerable information acquired about the development of boards and of clinics, a report "Community Child Health Centers: A Manual: 1979" was developed. This report and the accompanying operations and procedures manuals based on our experiences in pilot communities has been made available to boards of developing clinics.

Roles of CHSC and Community Groups


COMMUNITY NEED EXISTS
CHSC STAFF EXPLAIN THE CONCEPT
TASK FORCE
CHSC PARTICIPATES
MADE UP OF COMMUNITY PERSONS
ADVISORY COUNCIL consumers, DHS, AEA, PH, etc.
COMMUNITY PERSONS ARE THE MEMBERS
CHSC EMPLOYS AND ASSURES TRAINING
CENTER CORE STAFF - employed by CHSC (physician PNP secretary)
COMMITTEES established and contributed staff identified
- Integrated Evaluation & Planning Clinics initiated
- Other clinic and community programs added according to community need

In 1977, the Office of Maternal and Child Health and the Office of Special Education and Rehabilitative Services (U.S. Department of Education) requested grant applications for the development of integrated systems of services for children with combined educational and health problems provided by the combined efforts of state educational and state health agencies. A five-year grant was awarded to Iowa to begin the project. Later, additional funding from the Iowa State Legislature provided the basic support to enable this agency to expand and develop a comprehensive statewide system of regional centers.

CHSC Regional Service Areas


SPENCER
MASON CITY
SIOUX CITY
FORT DODGE
WATERLOO
CARROLL
DES MOINES
IOWA CITY
DAVENPORT
COUNCIL BLUFFS
OTTUMWA
CRESTON
BURLINGTON
CHSC Regional Centers—Small Town and Rural Areas
CHSC Regional Centers—Urban Areas

There are now 12 such centers functioning in Iowa. The centers are community-directed coalition efforts, functioning on a secondary level as a part of a stratified system of health care. They provide diagnostic services,

SUMMARY OF DEVELOPMENT OF REGIONAL CHILD HEALTH CENTERS

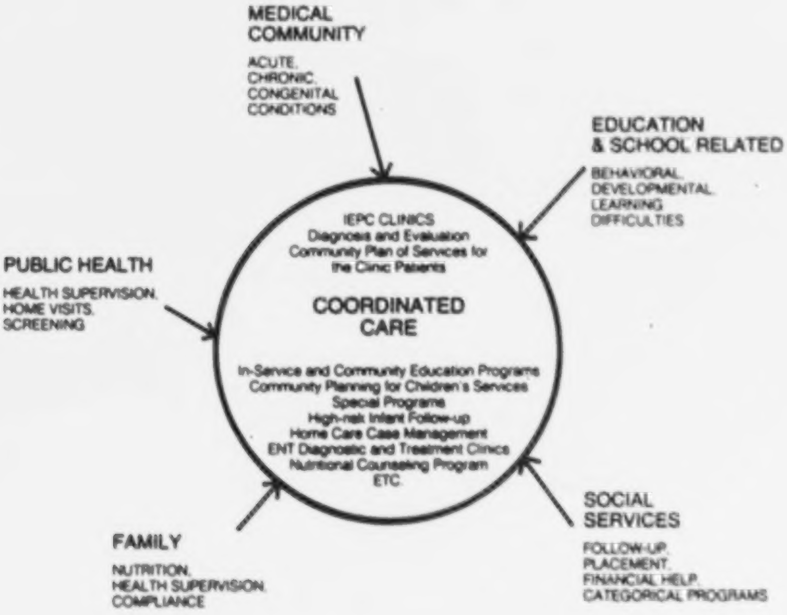
PERIOD	ACTION	OUTCOME
1975 Initiation of the concept of Regional Child Health Centers	Publication of the report "The Provision of Contemporary Child Health Services through Community Child Centers"	1. CCS operating funds diverted to implement idea
1976 Pilot projects	Pilot projects were developed in Ottumwa and Red Oak	1. The need for the service was shown 2. Physicians were interested in participating 3. Community organizers were employed
1978 Special Project Period	A competitive MCH/Education grant was obtained jointly with the Iowa DPI to conduct regional Integrated and Evaluation and Planning Clinics in 8 regional centers	1. Community councils were organized 2. Arrangements were made to train community pediatricians to work in the centers 3. Operational policies for regional centers were developed
1982 Green Book Legislation	The 70th General Assembly of the Iowa Legislature charged SCHS/MCH/DHS/Education to study 1. Location 2. Joint employment 3. Development of common procedures, etc.	1. Green Book report - January 1983 2. Creation of State Agency Coordinating Committee - 1983 3. Establishment of two pilot programs - Ottumwa/Sioux City (1983) 4. Two more programs established (1984)
1983 State Supported Regional Clinics	State support for regional clinics was obtained	1. Community financial participation obtained 2. Sliding fee schedule was developed 3. Site visit by AAP Comm. on Community Pediatrics
1984 Networking Services Grant	A competitive MCH grant to demonstrate networking of services was received	1. Pilot projects developed 2. Interagency communication system initiated 3. Special programs begun

case planning and follow-up. Inservice education and training are significant components. Various specialty health programs have been added to the regional centers beginning with the addition of a statewide high risk follow-up program, and now with the introduction of the home care program for chronically ill and technology-dependent children. Community planning by major agencies and local groups is being carried out. About 83% of Iowa's children in 84 of Iowa's 99 counties have some or all of these services available to them.

Center Organization

It is important to note that operation of the center and its clinics and programs are based on a voluntary coalition of agencies. Each agency commits staff time and resources.

REGIONAL CHILD HEALTH CENTERS
Essentials of the Program
Voluntary Coalition


MEDICAL COMMUNITY
ACUTE, CHRONIC, CONGENITAL CONDITIONS
EDUCATION & SCHOOL RELATED
BEHAVIORAL, DEVELOPMENTAL, LEARNING DIFFICULTIES
PUBLIC HEALTH
HEALTH SUPERVISION, HOME VISITS, SCREENING
IEPC CLINICS
Diagnosis and Evaluation
Community Plan of Services for the Clinic Patients
COORDINATED CARE
In-Service and Community Education Programs
Community Planning for Children's Services
Special Programs
High-risk Infant Follow-up
Home Care Case Management
ENT Diagnostic and Treatment Clinics
Nutritional Counseling Program
ETC.
FAMILY
NUTRITION, HEALTH SUPERVISION, COMPLIANCE
SOCIAL SERVICES
FOLLOW-UP, PLACEMENT, FINANCIAL HELP, CATEGORICAL PROGRAMS

CHSC provides office space, telephone, operating expenses, and the core health component for each center. The health component includes a community based physician, normally a pediatrician, with special training in developmental pediatrics. The physician serves as the medical director of the child health center and is reimbursed for professional services by CHSC. The health coordinator for each center is a pediatric nurse practitioner (PNP) or RN trained at the University of Iowa in a continuing program of inservice education. The centers include also a secretary employed and trained by the CHSC who serves as office manager and provides important support.

The Area Education Agency is asked to contribute its staff, primarily psychologists or speech-language and audiology consultants, educational strategists, physical and occupational therapists, depending upon the child's needs. The Department of Human Services is asked to contribute a skilled caseworker who can assess family strength and needs, and who also has knowledge of income maintenance support programs. The Department of Health is asked to provide the support of its visiting nurses or public health nurses who are able to make home visits and assist in providing health supervision following the day of the clinic.

Nutritionists also provide counseling for children with chronic nutritional diseases: failure to thrive, markedly obese and at risk for coronary disease.

The multidiscipline and multiagency staffing pattern of the centers makes them quite different from traditional child care agencies where each complement of professionals duplicate examinations already done in the community by professional staff from other agencies. Instead, those in the community who have examined children and provide direct services to them meet to work cooperatively.

Common Features

Although there are significant demographic differences in Iowa, each of the 12 centers share certain common features:

All regional centers have Integrated Evaluation and Planning Clinics (IEPC). The name of this clinic represents the initial purpose of the center. The IEPC services provided to a child are *integrated* into a comprehensive system. The IEPC are *evaluation* clinics because their function is to evaluate, not treat children's needs. At the clinics *plans* are developed to provide services for each child which will be implemented at the community or regional level. A part of each plan is a list of agencies involved in the child's care, the individual representing that agency, a designation of services to be received from the agency, and an outline of follow-up services (see Appendix-II). Last, it is a *clinic* in which a number of disciplines can function in a coordinated sequence to evaluate the child and to assist the family. The focus of the IEPC is to develop a community team of professionals from various agencies working together to provide services for a single child. A network of providers for each child is created which in no way decreases the autonomy or the mandated charge of any agency.

Not all children, e.g., the child who has uncomplicated educational problems, need to be seen in the center by all the examiners. They will continue to be seen in school, human service centers, etc.

Follow-up and implementation of the child's plan of care is the responsibility of the parents and the referrer. The clinic monitors any medical recommendations and treatment if the family has no local physician.

The centers are directed by an advisory council made up of the representatives of the major child care organizations in the community and representatives of consumers. Physicians and other professionals work on a coordinated basis and receive additional training provided by CHSC necessary to become more proficient in provision of new services for children.

The center must be part of a three level system of care for children with chronic illnesses and handicapping conditions. The children and their families must be able to move with ease and without disruption in the services provided between primary medical care, tertiary medical care and the secondary care provided in the center. The centers provide the least duplication between public agencies serving handicapped children. The centers are accessible to the patient and their families without the requirement of traveling long distances to a major tertiary level center. Patient costs are quite reasonable for an evaluation by a multidisciplinary team. The centers are an accepted community service arm of the traditional health, education and social service providers and provide a neutral meeting place where professional staff from these agencies can assemble. The center is not an educational, social service, public health nor medical clinic; it is a combination of all professions providing special services.

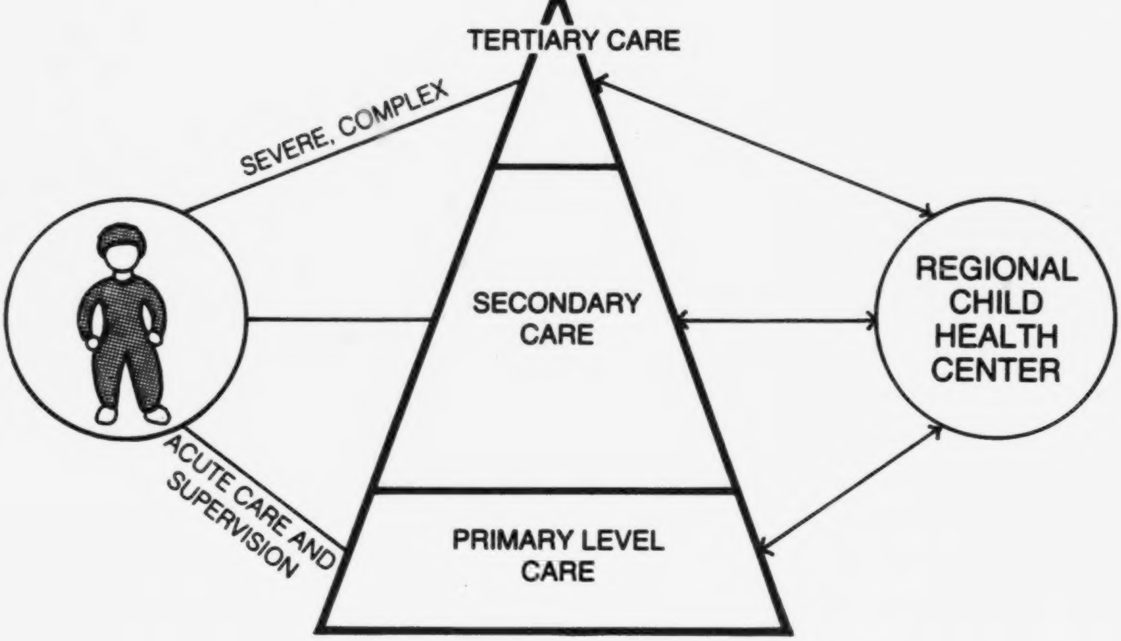
This system can be operated at a relatively modest cost for each of the participating agencies. At present, in our experience, the child health centers in Iowa represent a cost to Child Health Specialty Clinics of about $40,000 to $50,000 per center depending on staffing patterns for the provision of the core professional staff persons and support costs. There is little significant new cost to other agencies since their contribution is that of staff already employed.

The question of, "Whether networking through regional child health centers with services contributed from various agencies and community programs is possible in other states or is it a product of the peculiar circumstances, demographics and the structure of various service agencies in Iowa?" may be raised. From our experience we believe that this integrated network approach is not only possible but desirable and can be replicated in most areas of this nation. Its success depends not on geographical factors, but on major agencies entering into joint arrangements to provide services on a coordinated basis.

In summary, this regional system of centers has been important in balancing control of public programs designed to provide services for children with handicaps or chronic diseases between state programs and community needs. It was our goal to create the local capability to determine needed services, to monitor the provided services, to decrease the fragmentation of services for this population of children, and to create a system to provide comprehensive, contemporary health services not normally provided by either a private physician or a tertiary level medical center.

IV. A Stratified System of Care Needed for Chronically Ill and Handicapped Children

The System of Care for Children


TERTIARY CARE
SEVERE, COMPLEX
SECONDARY CARE
REGIONAL CHILD HEALTH CENTER
ACUTE CARE AND SUPERVISION
PRIMARY LEVEL CARE

Children and the Stratified System of Care

It is important to recognize that the regional centers and the integrated clinic programs function as a part of the stratified system of health-care as it has been developed in this nation. Until the 1930's with almost all medical care provided by general physicians the American health-care system was a single level system. With the emergence of various academies of medicine, pediatrics and orthopedic surgeons for example, and the development of medical education on a scientific basis, a secondary level of care began to emerge with specialists located in regional hospitals. As a result, the American health-care system became a two level system during the 1930's and 1940's.

With the nation's commitment to the support of biomedical research, great progress has been made during the last three decades in identifying new medical information which has been translated into new services to prevent, identify, diagnose and treat complex diseases and disorders. Many of the new services require physicians to be trained in subspecialities, in the use of complex and sophisticated equipment in expensive new facilities and to be supported by trained personnel working in the medical centers. The traditional two level system of primary and regional care could not satisfactorily provide these new services. It was necessary to develop a new level of health care that could provide the new, high technology tertiary level services. This resulted in the development of the three tiered American health-care system.

Just as there must be a three tiered system of health services (primary, secondary and tertiary) for children with acute disease if they are to receive comprehensive services, so there must be a three tiered system of health services for children with chronic illness and handicapping conditions if they are to receive the unique services that they require.

The tertiary level services for these children are well organized and are located in major medical centers. These centers will continue to provide a major part of specialized diagnostic-treatment services needed by this population of children.

However, there is essentially no organized system to provide secondary level services for children with chronic illness and handicapping conditions. The primary medical care system provides services for these children in the local community. Although primary medical services are in general adequate, educating private care physicians about the ongoing needs of these children would strengthen the system. The problem has been to determine what services these children need and to develop a delivery system to provide those services.

The present American medical care system is not designed to provide these services. The reasons for this include the fact that many of the programs were designed some time ago and are out-of-date; most of the programs are designed to provide services for traditional health problems and not to provide services for contemporary health and health-related problems; and, some of the programs were developed to provide only categorical services.

Made aware of these trends, the Iowa Child Health Specialty Clinics (formerly Iowa crippled children's program) conducted a series of surveys and studies in an effort to determine what services were needed by children and the system through which those services should be provided.

By studying those demonstration projects CHSC identified what services were needed, the characteristics of those services, and how to provide the services most effectively and efficiently with the lowest cost. This effort was most important because essentially no literature existed which described the special types of secondary level services needed by children with chronic illness and handicapping conditions.

On the basis of the CHSC studies, it was determined that the following services are needed:

- Certain level II medical diagnostic and treatment services that can be appropriately provided in the community.

- Certain technical care determined by a tertiary care center to be needed and can be provided in the child's home and community.

- Coordinated services needed by children with behavior, education and developmental problems.

- Community level child and family support services, i.e., case management services, respite care, etc.

- Contemporary preventive and early recognition health educational services.

Obviously, these services are very different in kind from those needed by children with acute care needs. One of the features of the services needed by children who have chronic illness and handicapping conditions that is different from the services required by children who have acute care problems is that children with chronic conditions require services over a longer period of time and require care as provided by several professional providers--often from more than one public agency, program, or provider. Therefore these services must be closely coordinated. Because coordinating or networking cannot occur spontaneously around each child's problem, to be effective it must occur in a reasonably organized framework. One of the major reasons for developing this regional system of care is to make coordination of services--networking--possible.

Further, during the recent period of rapid growth in medicine and in the physicians' ability to recognize and to treat organic disease, members of our society have become impatient with the lack of progress made in prevention and early recognition of disease. They have become aware that the lack of coordination increases cost of care. There is no doubt that through the legislative political process cost containment is demanded.

Another reason for developing the secondary system of care is the tendency for tertiary level providers to move into this void and assume the responsibility to provide these services by developing or expanding specialty clinics. This method must be questioned because it is impossible for a centralized program to utilize effectively the community resources available to the children. It is impossible for each tertiary level categorical program to solve the problem by having a local or regional nurse.

Lastly, most of the care needs that the children and their families need are generic and concerned with organizing community resources and services into a system adapted to a particular child and family.

Thus, the case is made for the need to develop a new system to provide a network of new services required by contemporary health problems. With very few exceptions, secondary level care for children with chronic illness and handicapping conditions does not exist. At this time, when all aspects of the American health care system are being reviewed and modernized, it is reasonable to suggest that a new system to provide secondary level services for children with chronic illness and handicapping conditions be developed.

The Secondary Level Regional Child Health Center

1. makes available, in the child's community, certain Level II medical diagnostic and treatment services;

2. makes available, in the child's home/community, certain technical care that is recommended by the tertiary center;

3. makes available, in the child's community, the coordinated services needed by children with behavioral, educational, and developmental problems;

4. makes available coordinated community level child and family support services, i.e. case management services, respite care, etc.; and

5. makes available a variety of contemporary preventive, early recognition, health-education services that are related to chronic health problems and that require secondary level care.

Those who speak for public community-based services recognize the importance of tertiary care and primary care, but if comprehensive services are to be provided, then arrangements must be made to assure that all the services listed are available.

In densely populated areas, a tertiary level medical center can provide services #1 and #2 listed above. They will not normally provide service #3 and do not have the capacity to provide services #4 and #5. Since much of the country is not densely populated, medical centers do not provide services #'s 2, 3, 4 and 5 listed above.

Similarly, it is impossible for the private medical care system normally to provide services for these children because (a) the private medical office is designed as a place to provide acute care and is not designed as a place for the team of health providers needed to provide the services to function, (b) the medical care system is not designed to provide services #'s 3, 4 and 5 listed above, and (c) the systems that pay for medical care do not pay for the services #'s 3, 4 and 5 listed above.

The organized arrangements to make sure that these services are available will differ from area to area in the country and, in many cases, will require the creation of a new regionalized system of care.

No one questions that tertiary medical care is necessary to provide modern highly technical diagnostic and treatment services for these children nor that it will continue to be a necessary part in the provision of services for many children with chronic illnesses and handicapping conditions. The question arises of how much primary and secondary care the tertiary centers can or should provide. In some urban areas where there are children's hospitals they have come to provide a great deal of primary and secondary care through the development of specialized outpatient clinic programs that are designed to provide comprehensive care. However, it is unlikely that in urban areas these services are sufficiently available to provide all the services for all the children with chronic illnesses and handicapping conditions and certainly most children in the nation do not live in metropolitan areas and do not have access to such care.

The absence of this secondary level-coordinated team has prevented the complete diagnosis and care planning services for many handicapped children or those with chronic diseases and illnesses. The regional center fills this void by making available coordinated services of various professions who can consult with each other and provide the diagnostic evaluation which these children require. Some children's needs are so complex they require subspecialists in large medical centers where high technology care for very complex health problems can be provided. However, the utilization of the secondary level service for handicapped children prevents the unnecessary over-utilization of more expensive tertiary level services.

Finally, during the last 50 years many physicians, nurses, occupational and physical therapists, speech and hearing personnel, psychologists and social workers have provided services for handicapped and chronically ill children. From that experience a body of knowledge has been developed about the modern technical services needed by handicapped children with different handicapping diseases and disorders. In addition, a consensus has also developed that these services should be provided in a unique supportive fashion if they are to be effective. The following standards of care have been agreed upon.

- care must be family based;
- care must be personalized;
- each child must have an individual plan of care;
- coordinated interprofessional team care must be available because most handicapped children have more than one problem;
- one person should be responsible for assisting the family to carry out the program; and
- the cost of the program must not destroy the family's finances.

Thus, both the technical and the support services required by handicapped and chronically ill children are very different from the services required by children with acute illness. These differences are so great as to make it necessary to organize special systems to provide services for handicapped children. The regional child health centers functioning on a secondary level are the system we have designed in Iowa to meet this need and do so according to these standards of care.

V. Results: The Creation of a System of Services

COMMUNITY BASED SYSTEM TO PROVIDE CONTEMPORARY CHILD HEALTH SERVICES

FEDERAL

(Office of Maternal & Child Health)
MCH   CC   SIDS   Hemophilia   Genetics

Child Abuse   Title I Program   Head Start   Voc Rehab   WIC Program   Migrant Program   Day Care

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STATE

Dept. of Health
MCH   SIDS   Health Education   Genetics   WIC

Board of Regents
CHSC

Dept. of Human Services
EPSDT   Child Abuse   DD-MR

Dept. of Public Instruction
Special Education

Volunteer Health Programs

STATE AGENCY COORDINATING COUNCIL

REGIONAL GOVERNMENT

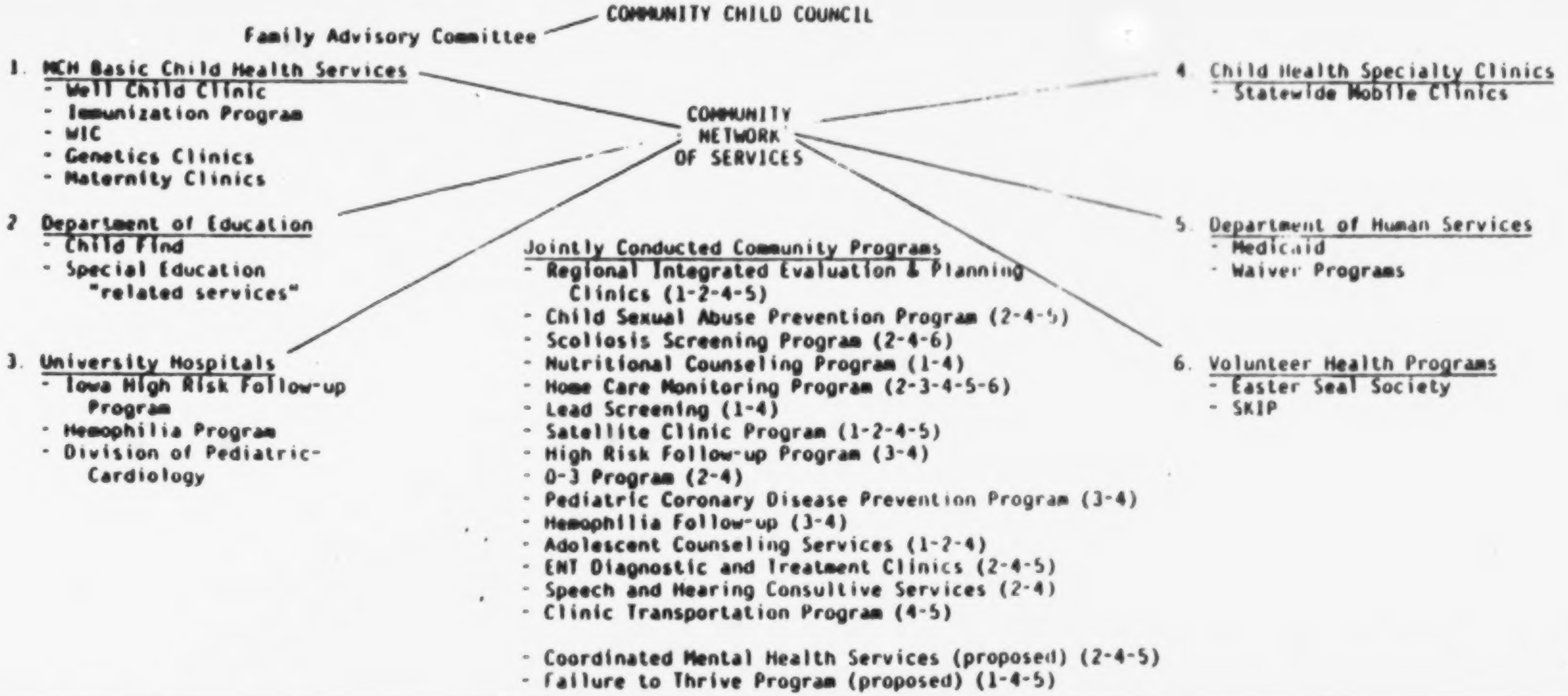
Regional Office
Maternal & Child Health Program
Department of Health

Regional Office
Child Health Specialty Clinics

District Office
Department of Human Services

Area Education Agency Office
Division of Special Education
Department of Public Instruction

COMMUNITY



COMMUNITY CHILD COUNCIL

Family Advisory Commitee

COMMUNITY NETWORK OF SERVICES

1. MCH Basic Child Health Services
   - Well Child Clinic
   - Immunization Program
   - WIC
   - Genetics Clinics
   - Maternity Clinics

2. Department of Education
   - Child Find
   - Special Education "related services"

3. University Hospitals
   - Iowa High Risk Follow-up Program
   - Hemophilia Program
   - Division of Pediatric-Cardiology

4. Child Health Specialty Clinics
   - Statewide Mobile Clinics

5. Department of Human Services
   - Medicaid
   - Waiver Programs

6. Volunteer Health Programs
   - Easter Seal Society
   - SKIP

Jointly Conducted Community Programs
- Regional Integrated Evaluation & Planning Clinics (1-2-4-5)
- Child Sexual Abuse Prevention Program (2-4-5)
- Scoliosis Screening Program (2-4-6)
- Nutritional Counseling Program (1-4)
- Home Care Monitoring Program (2-3-4-5-6)
- Lead Screening (1-4)
- Satellite Clinic Program (1-2-4-5)
- High Risk Follow-up Program (3-4)
- 0-3 Program (2-4)
- Pediatric Coronary Disease Prevention Program (3-4)
- Hemophilia Follow-up (3-4)
- Adolescent Counseling Services (1-2-4)
- ENT Diagnostic and Treatment Clinics (2-4-5)
- Speech and Hearing Consultive Services (2-4)
- Clinic Transportation Program (4-5)

- Coordinated Mental Health Services (proposed) (2-4-5)
- Failure to Thrive Program (proposed) (1-4-5)

COMMUNITY SYSTEMS PROVIDING CHILD HEALTH CARE

PRIVATE MEDICAL CARE SYSTEM

PUBLIC EDUCATION SYSTEM

SPECIAL EDUCATION
P.L. 94-142

PUBLIC HUMAN SERVICES SYSTEMS

LOCAL HOSPITAL SYSTEM

A Service System

The goal of CHSC to develop the regional child health centers into a system of consolidated support services provided to chronically ill children into an integrated, coordinated network of modern services required by the population of children referred to as the new morbidity has been realized. The desirability of having a single entry site into the service system was easily appreciated but the basic problems in implemention of the concept was that the services and programs provided by various agencies such as education, medical and human services are very different and require various types of facilities. Two possible solutions which recognized these differences were considered. The first solution to the provision of services was the development of a computerized information-collecting system which constituted a functional single entry system but not a single physical entry site in which these services may be provided. This will be described in more detail later.

The second approach was the development of a coordinated network or array of services shown in the organizational chart which identifies those services that could be provided jointly in a community under the umbrella of a community council or advisory board. This network of services was to be the heart of the regional child health center system (see previous chart). It would deal with the problems of fragmentation, lack of coordination and duplication in the services required by chronically ill and handicapped children. The CHSC pilot projects which began in the mid-1970's and the additional centers which began over the next decade have been successful in developing this coordinated network. Because each of the major state agencies have their own legislative authority, funding sources, rules and regulations, the coordination of these agencies into a network avoided the overwhelming problems of attempting changes in the organization of state agencies. It must be emphasized that participation in this network is voluntary, state agencies do not lose their identity and are actively involved in the creation of shared programs.

Community Boards/Councils

The community-based regional Advisory Board concept is essential to the development of this coordinated network system. The Board or Council (both names are used depending on the center's organizational structure) sponsors the center and selects the services most needed in that area of Iowa.

Except for an area of 8 counties in northeast Iowa, a statewide network of regional councils was completed in January, 1986, when the last two centers were opened (see map p. 16). The 16 counties in and around Iowa City, Dubuque and Marshalltown are served by the CHSC central office in Iowa City.

A special workshop was conducted in January, 1986, for the 12 regional centers as a part of the 50th anniversary celebration of the passage of the Title V legislation which established the MCH and CC programs. Each council identified barriers to coordinated services, needs of the children and steps necessary to introduce new services. A comprehensive planning document will be compiled for the entire state from the information currently being assembled on each center.

Several important models of the regional councils have emerged from the 12 regional councils and two special projects in Ottumwa and Sioux City established in Iowa.

The Executive Committee

Basic to all councils is the Executive Committee composed of 4-6 representatives or administrators from: Child Health Specialty Clinics, the Area Education Agencies--Division of Special Education, Department of Human Services District Office, and usually local hospital administrators. Representatives from Maternal and Child Health programs are also frequently members of this committee. The member agencies provide staff to the center, direction and planning, and may also contribute financial resources. The committee members are generally administrators in their own programs.

The Regional Advisory Board or Council

The regional advisory board or council is a broad-based policy-making board of 15-20 members, including the Executive Committee, parents of handicapped children, and professional support personnel such as vocational rehabilitation, public health nursing, school nurses, city council, WIC, teachers, etc. The advisory board is concerned with planning services for children in the region, legislation, public relation activities, inservice education programs for the community. This advisory board sets the direction for the center, serves as a sounding board for needs and concerns, engages in community planning (see Appendix-III "Health Survey Report") and advocates for new projects. Staff allocation and assignments are directed to the appropriate agency representatives for decisions.

A Combination Model

The Executive Committee may serve also as one component of the advisory board. In this case, the Executive Committee meets frequently, usually monthly to oversee staff and operational matters. The larger advisory board meets semiannually or annually to receive an overview of the center's operation and to engage in community planning.

Special Projects

In late 1983, CHSC received a grant from MCH which provided special funding for the development of two special projects in conjunction with the Iowa Department of Health. These two pilot projects conducted by CHSC and Iowa MCH in two centers, Ottumwa and Sioux City, further illustrate regional differences and the necessity for flexible arrangements because of demographic differences and the needs of the regional programs. The Ottumwa region is quite rural with a small population spread throughout a large geographical area. In the Ottumwa pilot project, the members of the center's Executive Committee became the planners for the pilot project and have broadened their focus to general issues for the entire area, such as transportation, access to primary level health, social service, mental health and educational needs of children throughout the region. The regional center is well staffed and directed, runs smoothly and requires relatively little oversight by the executive committee which now meets infrequently. In contrast, Sioux City region includes a large urban area with a large Native American population located in a small geographical area and had little previous experience with interagency cooperation. The committee of the Sioux City pilot project, funded under this grant is composed of the major agency directors and has focused on cross-agency training programs, information and referral methods and a standard multiagency intake form. The regional center council meets regularly and is concerned with the operational programs of the regional child health center. These examples show that any attempt to impose a single predetermined model would have been met with resistance and failure.

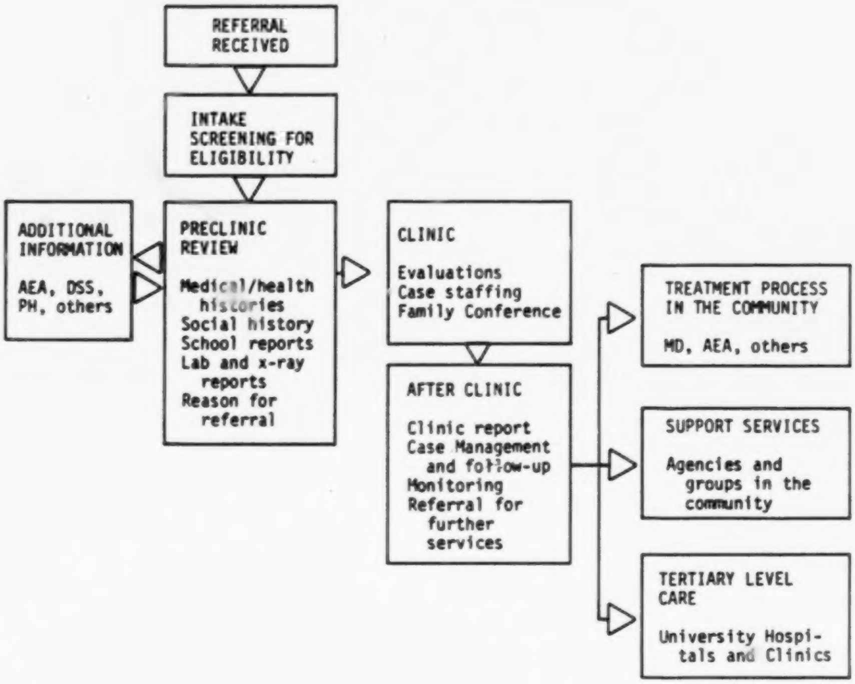
Thus, Child Health Specialty Clinics, area education agencies, district departments of human services, public health nursing, community hospitals, county medical societies, and other local groups have developed cooperative regional councils to provide integrated, diagnostic, and planning services for children with actual or suspected handicaps and/or chronic disease in the areas of health, education and human services.

A System of Services

The following activities of the regional center describe services for a new generation of children's health problems (see chart before p. 28).

The IEPC: The core of the regional child health center network is the Integrated Evaluation and Planning Clinic (IEPC) staffed by a multidisciplinary/multiagency evaluation team. It is the IEPC which provides high quality multidisciplinary diagnostic and comprehensive case planning services for children referred to the center with educational, behavioral and developmental problems. The IEPC process from referral to the clinic to referral for ongoing treatment is depicted as follows.

Integrated Evaluation and Planning Clinic Process


REFERRAL RECEIVED
INTAKE SCREENING FOR ELIGIBILITY
ADDITIONAL INFORMATION
AEA, DSS, PH, others
PRECLINIC REVIEW
Medical/health histories
Social history
School reports
Lab and x-ray reports
Reason for referral
CLINIC
Evaluations
Case staffing
Family Conference
AFTER CLINIC
Clinic report
Case Management and follow-up
Monitoring
Referral for further services
TREATMENT PROCESS IN THE COMMUNITY
MD, AEA, others
SUPPORT SERVICES
Agencies and groups in the community
TERTIARY LEVEL CARE
University Hospitals and Clinics

Summary of Characteristics of the Services Provided in the Center

- The services are organized to include professional multiple agency participation since many children require multiple professional assistance.

- The services are community based. Although a child may require specialized care, many of the support services needed by these children are generic and can be provided in the community.

- The services are family oriented. Children with chronic illnesses and handicapping conditions particularly need family support and the family needs community support services.

- The services are regionalized. Children with chronic illness and handicapping conditions represent a low-frequency, high-service, high-cost population and experience shows that the only way such services can be made available is by regionalizing those services to conserve resources.

- The services do not destroy the economy of the family. One of the ways of decreasing the costs of services is through the coordination of services.

- The services may well include certain technical care that has been recommended as a result of an examination in a tertiary center. Treatment plans as developed by a tertiary center may include follow-up diagnostic and treatment procedures that can be provided in the community.

- The services include a coordination of services needed by children with behavioral, educational and developmental problems. There is abundant documentation that there is an ever increasing number of children who have been identified as "the new morbidity." These children need access to representatives of education and mental health.

- The services provide family support. It has been documented that many children with chronic illness and handicapping conditions and their families have, over and above their need for technical care, the need for support services. These are for the greater part generic services needed by all children who have chronic illnesses. The organization of these services must be designed in the community by those who are to be involved with the provision of the care.

- The services must coordinate with other contemporary services including a variety of screening programs and early identification programs. Some of these are for targeted populations as the scoliosis screening program or for children who are obese. Some services are for a broad population such as programs for the prevention of sexual abuse.

A typical clinic day in which these services are provided can be seen in the following clinic day schedule for the Ottumwa area regional center.

Specialized Child Health Center Serving Area 15 Clinic Day Schedule

CLINIC DATE: **November 27, 198**

PATIENT'S NAME	DOB	SCHOOL-GRADE	REFERENT	PROBLEM	DISPOSITION
1 PM **Becky XXXXX** **Parent: Patricia XXXXX** **; Oskaloosa, IA** **MAHASKA CO.**	10/16/75	Jefferson, Osky Gr. 3 EMP SCI	Ada , AEA Oskaloosa	No bladder control day or night, worsened rec.	
2 PM **John XXXXX** **Parent: Tami XXXXX** **, Ottumwa** **WAPELLO CO.**	8/18/76	Agassiz, G2 MD	Gretchen and R. teachers	? physical cause for LD. Listless, tired, dark cir. eyes. No affect. Unable to sit comfortably in chair some days.	
2 PM **Daniel E. XXXXX** **Parent: Sherry XXXXX** **; Milton** **VAN BUREN CO.**	11/24/82	NA	WIC Program 317 Vanness Ottumwa	Premature. ? development Poor growth Crooked toe Mom re "fits," nightmares	
3:30 PM **Charles XXXXX** **Parent: Conni XXXXX** **; Ottumwa** **WAPELLO CO.**	11/9/81	NA	, WIC Program	Poor growth	
3:30 PM **Megan A. XXXXX** **Parent: Sheri XXXXX** **; Ottumwa** **WAPELLO CO.**	7/28/80	NA	E. W. , MD Ottumwa	Inappropriate behavior Need Psych.	
FOLLOW-UP VISITS:					
Lance XXXXX	1/19/78	FU Med.			
Michael XXXXX	6/13/77	FU Med. & Behavior			
William XXXXX	6/17/76	FU Lab data & dietary habits			

High Risk Follow-up Program: Each regional center has a High Risk Follow-up Program (HRFP) which is well accepted by the medical community and has been carefully integrated into the network of human service programs in each community. AEA Special Education Divisions provide a significant amount of follow-up services for children at risk who fail some aspect of the developmental screening evaluations. The regional high risk follow-up program is closely associated with the central research and demonstration program conducted by the University of Iowa Medical Center. The central program provides training for the regional pediatric nurse practitioner (PNP), the computerized information base and evaluation staff. Its pediatric nurse practitioners and physicians regularly make referrals to the CHSC regional service programs for follow-up evaluations for families who cannot return to the University of Iowa Hospitals and Clinics.

The high risk follow-up service programs have been so successful that physicians and other professional persons in the communities now refer other children with significant health problems, trauma, acute meningitis, etc., to the follow-up screening program. These children have been determined to be "at risk" for developing disabilities. Because the high risk follow-up program is research-based these children are periodically reevaluated, but their records are kept separate. Positive community response to "at risk" service programs indicate that there is a definite need for such children to be watched for developmental delays or other significant health problems, and followed by a network of community service providers.

The program continue to grow in size each year, and now require approximately 50% of the pediatric nurse practitioners' time in several centers because children are followed for sixty months after enrollment.

Home Care Support Program: Following the Surgeon General's conference on technology-dependent children held in Washington, DC in December, 1982, CHSC began to move rapidly in the development of a home care support program for infants and children requiring long term rehabilitation services and intensive home care. It was recognized that while many services are available through the usual health, education and social service providers, a case management approach was needed for coordination of an entire network of community services.

Agencies generally involved in the home care program are area education agencies, Child Health Specialty Clinics, Department of Human Services and volunteer health agencies. The target population are children with chronic diseases and/or who are dependent upon modern forms of technology for their survival outside of intensive care units. The purpose of the program is to provide an orderly transition from hospital nurseries to home, insuring medical stability for the child during the transition. The secondary purpose is to create a community care team to assist the family in providing for the many aspects of the child's needs: financial; personal; nursing; and, a wide variety of other support services. The CHSC home care program has been approved by the Iowa Department of Human Services to provide case management for "waiver" children entitled to services under Title XIX. A contract has been signed with Iowa Blue Cross/Blue Shield to provide the case management component for children covered by this major insurance carrier. Similar contracts are being negotiated with other insurance companies.

As an outgrowth of concern about the cost of providing long term highly technical care in hospitals, the concept of alternatives to hospital care with families providing a significant amount of patient care emerged. This arrangement has brought the families into the care team and they now are a new and major force to be considered in providing services for children with chronic illnesses and handicapping conditions.

Professional Inservice Training: In communities where regional child health centers are located, CHSC sponsors continuing education programs designed for those who work for the AEA, the school systems, and other community persons. The programs provide information about health and health-related problems that can delay development, result in physical disability, or in educational or behavioral handicaps. Sessions are presented by members of the CHSC and UIHC staff.

CHSC regional staff have sponsored or cosponsored many inservice programs, including programs about child abuse, newborn intensive care, anorexia nervosa and bulimia, Reye's syndrome, emergency care for children with learning disabilities, seizure disorders, developmental lags, and attention deficit disorder (ADD).

Service programs conducted in some centers but not in all centers are:

Child Sexual Abuse Prevention Program: The purpose of this program is to alert children to the possibility of sexual abuse, how to care for their own bodies in compromising situations, how to say "no," and where and how to seek help. The program also alerts teachers and administrators to the possibility of sexual abuse, to new curriculum materials and encourages them to include prevention programs as a part of the school curriculum. The program involves public schools, Child Health Specialty Clinics and the Department of Human Services. Workshops, assemblies, classroom presentations are the primary methods of reaching school age children and school personnel.

Scoliosis Screening Program: The Easter Seals Program of Iowa and CHSC provide training in scoliosis identification and referral to school nurses and other personnel. While some screening is done directly, the program focuses primarily on the training of screeners who will carry out the program in public schools.

Speech and Hearing Consultive Services: In selected regional centers special clinics are staffed by CHSC professional staff for children with severe or unusual speech/language problems referred by special education personnel. Area education agency Special Education Divisions and Child Health Specialty Clinics are involved in this program.

Nutritional Counseling Program: This demonstration project is designed to address the lack of a well-organized system for the provision of nutritional services to Iowa children who (1) have handicapping conditions and/or chronic diseases; (2) are at risk for the future development of coronary heart disease; or (3) have obesity problems. These problems have been documented at the national and state levels. The diseases or conditions mentioned are amenable to nutrition interventions which may be therapeutic, preventive, or both. Currently, regional dietitians are beginning to establish the nutrition program at each clinic site.

Pediatric Coronary Disease Prevention Program: The Pediatric Coronary Disease Prevention Program is a component of the Nutritional Counseling Program. It is an educational intervention for children who are at high risk for future coronary heart disease based on elevated serum cholesterol levels or a family history of one or more close relatives having had a heart attack at less than 50 years of age. These children and their families are taught about nutrition, diet, how to promote a healthy life style and other cardiovascular disease risk factors. Local community personnel and resources identify and refer the children and families in need of this program. Laboratory blood analysis and necessary medical follow-up are also included in the program. University of Iowa Hospitals and Child Health Specialty Clinics are involved in this program.

Clinic Transportation Program: Through cooperative efforts of Child Health Specialty Clinics and the Department of Human Services transportation is made available for children who would not otherwise be able to reach CHSC mobile clinics and regional centers. Thus far, this special project is limited to rural counties in southern and western Iowa.

Lead Screening Program: The target population is children and their families who have been exposed to high levels of lead in their environment. Medical attention is required for the elevated blood lead levels and environmental assistance to remove the cause of lead toxicity. Once the source of lead poisoning is removed from the environment, appropriate medical attention will be provided to reduce lead poisoning until the child's normal health can be restored, and referral made to special education if needed. Maternal and Child Health, public health services and Child Health Specialty Clinics share the responsibility for this program.

Satellite Clinic Program: The Satellite Clinic Program is an extension of regional IEPC in rural areas not well served by the regional center because of distance. Therefore, in selected areas the clinic staff (pediatrician, pediatric nurse practitioner, secretary, AEA psychologist, and DHS social worker) travel to a satellite site in outlying communities to provide clinic evaluations, staffings and comprehensive case plans. Maternal and Child Health, public health services, Area Education Agencies Special Education Division, Child Health Specialty Clinics and the Department of Human Services are involved in this program.

Birth to 3 Years of Age Program: The program essentially promotes better health for children from birth to age 3, education and family care for young children to insure their normal growth and development through inservice to persons who provide care for this age child. By agreement with the administrators of the Area Education Agencies a child followed in the High Risk Follow-up Program found to be developmentally delayed may be referred to an early childhood program, and a child found by the child find program to have signs of a medical problem may be referred to an IEPC clinic.

Hemophilia Program: The Hemophilia Program is an extension of the Iowa Rural Comprehensive Care Program for Hemophilia Patients and their families. It makes available on a regional basis nursing supervision, counsel and advice from CHSC professional staff. After a patient has been seen by the Iowa

Hemophilia Program either as an outpatient or inpatient at University Hospitals, the program then develops a plan of activities and services for the patient to be carried out in the patient's home and community under the direction and supervision of a regional CHSC nurse. The patient must return to the University Hospitals at stated intervals, but receives ongoing counseling from the regional CHSC nurse near his home.

Adolescent Counseling Services: A special pilot project is being conducted in one regional center, Ottumwa. An experienced psychologist from the University of Iowa Hospitals, Department of Pediatrics, conducts monthly counseling clinics. Young children and adolescents, who have a variety of somatic complaints, school refusal, and other preneurotic behavior patterns are served by the clinic. The clinic is supported by members from the Department of Human Services and the Division of Special Education.

ENT Diagnostic & Treatment Clinics: Special education, a physician provided by Child Health Specialty Clinic, nurse and representatives from other community programs provide the staff for this program. ENT clinics are held 1-2 times per month; children are referred by CHSC programs or physicians. Audiologists are provided by special education and services are diagnostic in nature with referral for ongoing care. If further evaluation or treatment is required, the patient is returned to the referring physician for ongoing medical care or the necessary surgical services. The Department of Human Services provides social work services to conduct interviews and assist patients and families eligible for DHS assistance.

Multiagency Information Systems

Important in solving the problems of fragmentation of services and of networking the efforts of several agencies into a coordinated interagency system is need for the expedient transfer of information about patients and the services provided to them. The use of written reports to communicate has proven to be very inefficient and unsatisfactory. CHSC is convinced that the answer to this problem is to be found in new computer technology which makes it possible for agencies to immediately transfer and to share standardized information. Such a system would, in effect, constitute a functional single-entry system, if not a single physical-site entry system.

CHSC staff have accomplished the following: (1) identification of core patient information needed to communicate among professions; (2) outcome indicators, including the Profile of Problems and Goals; (3) a computerized data/information system, incorporating service and outcome descriptors, and emphasizing the potential for multiagency use.

An automated patient information system has been developed, entitled Information for Assessment, Planning and Tracking (IAPT). The data base includes information related to patients such as: demographics, diagnoses and problems, care plans and their status, care providers, and outcome indicators. Unique features of the data base include individual service plan summaries, service plan status, status of diagnoses/problems, and ordinal-scale coding of the patient's functional status and prognosis. Features of the system include: multiagency sharing of demographic information, descriptions of individual agency care plans, care providers, and outcomes of care; automatic tracking and reminders of patient service needs; a capability for providing aggregated multiagency statistical information about the patients, their problems, and the care system; printing of patient information in prescribed formats.

Systems for collecting and processing patient information have been developed for the CHSC clinics, by incorporating limited data items into the professional clinic worksheets and by training clerical, word-processing and data-coding staff to translate the professional worksheets and reports into coded information. Similar systems and training have to be developed for other agencies which participate in the patient information system. The interagency patient information system has been installed in one region. The regional committee has expressed strong support to pilot the proposed system in the Ottumwa area. The MCH Networking grant provides financial support for this pilot during Fiscal Year 1986.

Four other regional centers now have terminals which provide access to central IAPT services. The remaining activities in the development of an interagency system include: (1) testing and refinement of the information system on a regional basis; (2) development of statistical report formats; (3) evaluation of regional and statewide data; (4) evaluation of the efficiency and effectiveness of the information system. The extension of the terminal network to all centers depends upon availability of funding.

Physician and Pediatric Nurse Practitioner Training: CHSC assures that community physicians and pediatric nurse practitioners who serve in regional child health centers receive the training necessary to upgrade their skills in developmental pediatrics. The training programs for both physicians and PNP are done in collaboration with UIHC Division of Developmental Disabilities. In FY 1986 special training was reinstated by teleconferencing (Telenet) and inservice conferences. Training for follow-up of high-risk infants is complete for all PNPs.

Charge Policy Introduced

In 1982, as a result of a directive from the Iowa State Legislature affecting Child Health Specialty Clinics, a charge for professional services was introduced for families seen in the clinic programs conducted by this agency. Based on a sliding fee scale, children from lower income families are not charged for professional services provided by CHSC. Those referred to the regional centers from middle or upper income families are charged according to their ability to pay (see Appendix-IV) and may receive third party reimbursement. However, the charge made for a comprehensive diagnostic consultation is determined on the basis of the complexity of the evaluation. The total charge for a complete professional evaluation does not exceed $90 for an "extensive" evaluation.

The following method is used to determine what portion of that cost is charged for services provided for any one child.

1. Families of low and moderate income below 150% of the poverty level $16,500 for a family of four effective 7/1/86) are not charged.

2. The carrier will be charged if the family has private health insurance or if they are eligible for Title XIX or CHAMPUS.

3. If there is no third party carrier or if the payment by a third party is incomplete and reimbursement has been authorized by the Area Education Agency, the AEA will be billed for any remaining charges.

4. Direct payment by the family is the last resource. The family's charge obligation is determined by the family size and income on the sliding scale that begins at 150% of the poverty level as defined by the U.S. Department of Health and Human Services. Families with income above that level are expected to pay a percentage of any charge remaining after reimbursement from third party resources.

5. No child will be refused service because of a lack of financial resources. Charges are waived in these cases.

Charge recovery is sought only for the direct patient services provided by the physician. A charge is not made for the important services contributed by the professional staffs of the Area Education Agencies, the Department of Human Services, and various other agencies.

Charges for support services--laboratory and x-rays--are in addition to the professional charge and are billed to third party carriers or to the family.

The policy to charge families, according to their ability to pay, represented a major change in this agency's history. Previously services were provided without charge. The Iowa State Legislature required the charge in order to extend public support and thus serve additional children and their families. Income received by the regional centers is used to reimburse the local physician.

VI. Data, Interpretation, and Center Evaluation

CHILD HEALTH SPECIALTY CLINICS
March 1986 - March 1987

PEDIATRIC CLINICS

COMMUNITY	DEVELOPMENTAL	CARDIAC	ENT	ORTHOPEDIC	INTEGRATED EVALUATION AND PLANNING CLINICS
Fort Dodge	3/13/86; 5/22/86; 9/4/86; 11/7/86; January 87; March 87	5/15/86; 11/13/86		4/24/86; 10/16/86	bi-monthly
Pocahontas			10/15/86		
Sioux City	3/27/86; 6/5/86; 9/18/86; 12/4/86; March 87	6/19/86; 10/16/86; February 87	10/18/86; February 87	7/10/86; January 87	bi-monthly
Spencer	4/25/86; 6/12/86; 8/7/86; 10/23/86; 12/2/86; February 87	5/22/86; 9/4/86; January 87	alternate months	6/10/86; 9/16/86; 11/5/86; February 87	(pending)
Storm Lake			4/22/86; January 87		
Decorah		7/29/86; January 87		3/13/86; 9/11/86; March 87	
Marshalltown	3/20/86; 9/23/86; March 87				
Mason City	5/12/86; 8/11/86; 11/10/86; February 87	6/10/86; 9/16/86; February 87		4/7/86	bi-monthly
Waterloo	7/8/86; January 87	4/2/86; 8/5/86; 10/8/86; January 87	4/30/86; 12/9/86	8/13/86; February 87	bi-monthly
Council Bluffs					
Atlantic	4/10/86; 7/24/86; 10/2/86; January 87	7/17/86; February 87	11/13/86; February 87	7/31/86; January 87	bi-monthly
Carroll	3/12/86; 5/1/86; 7/15/86; 9/10/86; 11/12/86; January 87; March 87	4/24/86; 10/2/86	monthly	5/15/86; 8/7/86; 12/2/86	(pending)
Creston		7/17/86; February 87	monthly (Sept-June)	7/31/86; January 87	bi-monthly
Burlington	5/20/86; 8/15/86; 11/25/86; February 87	3/4/86; 9/9/86; March 87		6/4/86; 12/10/86	bi-monthly
Fort Madison			11/4/86		
Davenport		monthly			bi-monthly
Dubuque		4/16/86; 5/6/86; 7/29/86; 9/24/86; 11/3/86; January 87; March 87		3/13/86; 9/11/86	
Oakdale		3/19/86; 6/25/86; 12/17/86			
Ottumwa		4/9/86; 11/19/86	4/15/86	6/4/86; 12/10/86	bi-monthly
Chariton	3/4/86; 5/28/86; 9/26/86; 12/16/86; March 87				
Des Moines				5/2/86; 11/14/86	weekly
Ames		7/10/86; January 87			

FOR FURTHER INFORMATION OR REFERRAL CALL: 319:353-5428

CHILD HEALTH SPECIALTY CLINICS
(State Services for Crippled Children)
University of Iowa
Hospital School Building
Iowa City, IA 52242

Nv:02/10/86

Integrated Evaluation and Planning Clinic appointments are handled via the appropriate Center.

Burlington	319:752-6313	Fort Dodge	515:955-8326
Carroll	712:792-5530	Mason City	515:424-7388
Council Bluffs	712:328-6798	Ottumwa	515:682-8145
Creston	515:782-6435	Sioux City	712:279-3411
Davenport	319:383-1441	Spencer	712:264-6362
Des Moines	515:283-6236	Waterloo	319:236-4560

Observation and Comment

The regional clinics function as one component of a wide range of specialty clinics conducted by CHSC. The schedule of Pediatric Clinics, March 1986-March, 1987, at the beginning of this section identifies the entire range of clinics. The data now to be discussed applies only to the Integrated Evaluation and Planning Clinics.

In planning for the regional centers in 1976, it was thought that the centers in the smaller cities and rural areas could be adequately staffed by half-time pediatric nurse practitioners and secretaries and hold 20 half-day clinics per year. In urban areas, it was projected to have full-time pediatric nurse practitioners and secretaries and hold at least 24 full-day clinics each year. In general, this is true but local circumstances have resulted in significant exceptions. In Ottumwa, for example, a rural area, the center has grown steadily. The nurse practitioner is currently employed 90% time and in addition is assisted by a half-time nurse and full-time secretary. Clinics are held frequently. In the large Davenport/Quad City area the integrated clinic has not been utilized as expected, but specialty services (high risk follow-up and cardiac consultation clinics) have been well-received. The large number of other local resources and proximity to the University of Iowa Hospitals is responsible for the lower caseload.

The development of the regional centers in rural areas such as Ottumwa in southeast and Creston in southwest Iowa was easier that in urban areas. Fewer resources were available for coordinating interdisciplinary services. Professional staff and administrators in these areas recognized the need for services that they could not provide alone and had a history of working together. In urban areas such as the Davenport/Quad City area in eastern Iowa and Des Moines in central Iowa, many resources offered similar services to families who could also afford private patient fees. The urban areas needed semi-tertiary level services, not the less sophisticated Level II services that the regional centers provided. Even the direction of highways affected the response to certain regional centers. In Iowa the major highway systems run east and west making the University of Iowa Hospital complex in Iowa City easily available to some communities and not to others.

Another local factor is the availability of professional resources, especially medical specialties such as otolaryngology. There were no otolaryngologists in the western half of the state before the Creston regional center was established. The board of the Creston center determined very early that otolaryngology services were a high priority for the area. This agency was able to provide equipment, and made it possible for University Hospital otolaryngologists and later otolaryngologists in private practice to serve the Creston area on a monthly basis. The AEA provided staff support and coordination of services. Until this fiscal year, Creston was the only regional center offering ENT services. Each year since the initiation of this special program 500-600 or more area children have been evaluated. In FY 1986, there were 787 children's appointments. Subsequently regional ENT clinics have been added in three additional central and western Iowa centers.

Population demographics also affect utilization of regional centers. In southern Iowa the population is relatively sparse and the percentage of people 60 years and over in several counties is 23%. The Creston area with 3,800 square miles served only 1,000 children in special education in the entire region when the center was established.

The children seen in the twelve regional centers reflect a cross-section of the population in the state. Only about 2 1/2 percent of the people in Iowa are minorities. Of this number, most of the minority population is black or Hispanic. Southeast Asians have been entering the state for the past five years in significant numbers and now make up a small minority group in several of the larger cities. There are also several Native American settlements across the state.

Personnel factors play a significant role and are reflected in the statistics. The Des Moines center shows a significant increase in use when in 1980 a new coordinator introduced a more diagnostic and community oriented model. The Creston center PNP, a very effective advocate for children and jointly employed by the AEA, left the center in 1981. For budgetary reasons she was not replaced. The use of a physician who did not understand fully the particular needs of handicapped children and their families is reflected in the statistics of another center.

While making the data more difficult to interpret, these variables are necessary for the centers to be truly regional. For the centers to succeed they must be adapted to the circumstances of the locale, to the professional staff and to the families served.

Because the regional centers vary considerably in the services they provide and because of many local characteristics, the following data have been selected from particular centers; however, it is representative of most, if not all the centers.

Detailed statistics on all mobile and regional center programs are available from CHSC offices in Iowa City, Iowa (see also Appendix-V for recent data from the Waterloo Child Health Center).

Sources of Referral to Regional Centers

SOURCES OF REFERRALS IN PERCENT
1984-1985

	RURAL		URBAN	
	Mason City	Ottumwa	Des Moines	Sioux City
Area Education Agency	19.3	33.6	24.2	26.7
Teacher/Principal	4.4	6.7	10.0	8.9
School Nurse	34.2*	10.9	4.2	2.2
Physician	11.4	23.5	19.4**	8.9
Parent	9.6	7.6	7.6	35.6**
Department of Human Services	7.0	11.8	19.4	4.4
Public Health Nurse	13.2	1.7	1.9	2.2
Preschool/Head Start	--	1.7	3.3	2.2
Other	0.9	2.5	10.0	8.9

*Referrals made as a matter of practice by the school nurse rather than other school personnel.

**Parents are asked by the physicians to refer their children.

The largest number of referrals to the regional centers is through the local and intermediate education agencies, which corresponds to the large percentage of children ranging in age from six years to eleven years of age. Local physicians now refer a sizable proportion of children to the centers indicating acceptance of the centers by the local medical community. Parents, very often on their own or more likely on the advice of a health professional, bring their children to the center for evaluation. The remaining referrals are made by preschools including Head Start, public health nurses, Department of Human Services, MIC and WIC. Because so many of the referrals are made by schools are related to behavior and learning disorders the ratio of boys to girls ranges from 1.9 to 2.8.

In addition to the large proportion of boys referred to the centers, we found that referrals follow the school year and are highest in the fall and spring months and lowest during school vacations, mid-winter and summer.

Data regarding referral sources is "skewed" because some AEAs insist that all children in special education be referred by AEA personnel and others prefer the parents or family physician to make the referral. These differences are reflected in regional child health center statistics.

Referrals Made from the Regional Centers

REFERRALS MADE BY OTTUMWA CLINIC TO AGENCIES
AFTER PATIENT EVALUATION BY PERCENT

	1984	1985
AEA Services	25.0	8.0
Mental Health	8.4	28.0
Local Specialist	21.7	--
UI Hospitals & Clinics	18.3	52.0
Genetics Clinic	18.3	4.0
Department of Human Services	8.3	--
Women, Infant & Children Program	--	8.0

Of particular importance has been the recognition that about 90 percent of all referrals throughout the state that are made following evaluation in an IEPC are to local resources--especially to the AEAs, local physicians, etc. This recognition supports the conviction that the majority of children in need of secondary level evaluation services can receive the ongoing treatment services they require locally. In other words, most of the services required are available if a secondary level evaluation is completed, a case plan prepared which specifies the needed services and in what sequence, and responsibility for providing those services is assigned.

The Table of Referrals from the Ottumwa Center also indicates in that area of the state mental health services for children are a significant need; some children are also referred to the Level III University of Iowa Hospitals and Clinics for further testing and treatment.

Parents can very often handle the necessary treatment arrangements at home without further assistance from community resources other than information. Some children are referred directly to community agencies such as, in Sioux City, Indian Health Services, Big Brother/Big Sister, Department of Human Services, or to the education agencies.

Referrals to Clinics by Age of Children

REFERRALS TO CLINICS BY AGE OF CHILDREN IN PERCENT

1984-1985

YEARS	RURAL*	URBAN**
0-1	2.6	2.4
1-2	5.7	14.2
3-5	22.4	26.4
6-11	52.2	46.2
12 & Over	17.1	10.8

*Ottumwa and Mason City combined

**Des Moines

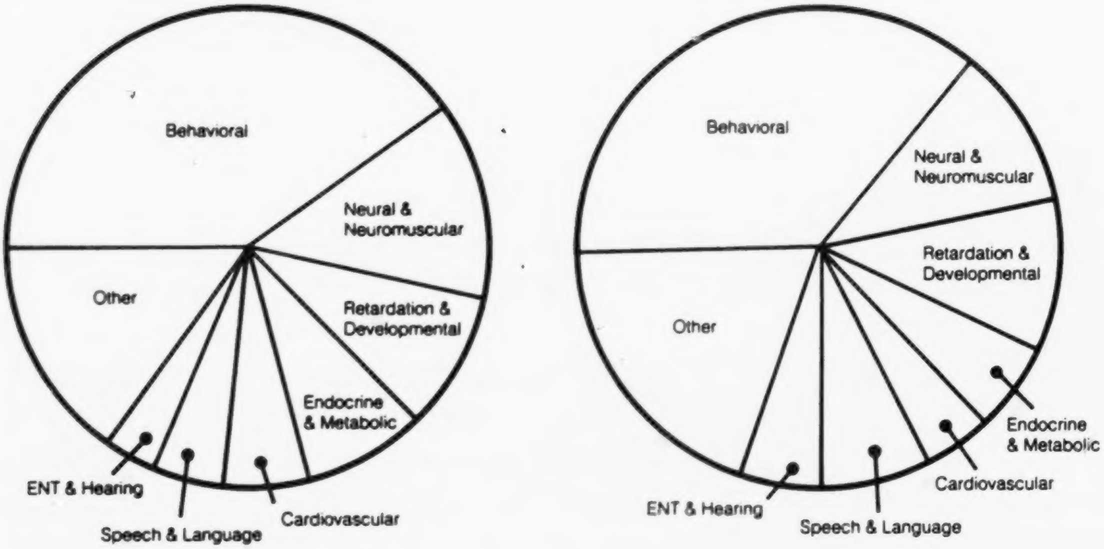
The large majority of children referred to the regional IEPC are preschool and elementary age children. This data reflects the close association of the regional clinics with the education system. Also, many of the problems which the regional clinics can serve well are associated with behavior and learning problems which typically are not referred for evaluation until the preschool or elementary school years. Adolescent problems requiring evaluation have not been as well served by the regional clinics: drug abuse, teenage pregnancy, mental health problems, etc. The issue of mental health services for children and adolescents, however, is an issue being addressed by this agency at the present time. A pilot project has been carried on for two years in Ottumwa. An experienced psychologist from the University of Iowa Hospitals and Clinics conducts weekly or bi-monthly clinics in the area. The type of children seen in this pilot project are children with school refusal, behavioral problems and somatic complaints. The community's very positive response to this special project indicated clearly the need for the addition of mental health services to the regional clinics.

Types of Handicapping Conditions Seen

The majority of the children referred have a broad range of medical, developmental, behavioral, and educational problems. The statistical information on the types of problems seen is as follows:

Behavioral	40.8%
Retardation & Developmental	13.8
Orthopedic	3.7
Speech & Language	6.0
ENT & Hearing	4.5
Cardiovascular	3.2
Respiratory	3.0
Other	14.3

Handicapping Conditions at
Integrated Evaluation and Planning Clinics



a. Primary Conditions

b. All Conditions

The largest group of children referred are for a combination of behavioral, emotional and social problems, especially hyperactivity or Attention Deficit Disorder. Children with medical problems are also a large group including a broad range of developmental delay problems, enuresis and encopresis, obesity, urinary incontinence, problems of neurological dysfunction, etc. The behavioral and school-related referrals include problems with peer relationships and a variety of social and emotional problems involving poor self-esteem, uncontrollable behavior, and other problems associated with unstable family conditions.

Clinic Days and Clinic Attendance

5-YEAR STUDY OF THE NUMBER OF CLINIC DAYS AT REPRESENTATIVE CENTERS

(Note: depending on local circumstances, length of "clinic day" varies from 2 1/2 hours in Des Moines to full days in Waterloo.)

	1981	1982	1983	1984	1985
			RURAL*		
Creston	11	12	11	10	10
Fort Dodge	13	--**	21	20	19
Mason City	30	26	23	21	29
Ottumwa	24	24	29	37	38
			URBAN		
Davenport	17	17	16	14	10
Des Moines	52	92	119	122	129
Sioux City	16	12	17	18	21
Waterloo	27	26	25	32	39

*Rural center has no metropolitan area with a population of 50,000. Urban center has at least one metropolitan area with a population of 50,000 or more.

**Fort Dodge was closed during 1982 because of budget cuts.

As with the services offered by each regional center the number of days that clinics are held throughout the year reflect the needs of the community. In 1985, 295 integrated clinics were held across the state. The number ranged from a low of 10 days at Creston and Davenport (one per month) to a high of 129 in Des Moines. Creston is in a rural area with a low density population and many elderly while Des Moines on the other end of the scale is a metropolitan area with a population of about 250,000. Davenport is also a metropolitan area but the acceptance of the clinic has not been as great as in the remainder of the state. The low usage of the Davenport clinic may reflect the fact that the University of Iowa Hospitals and Clinics are only about a fifty mile drive on an interstate highway and people tend to use this tertiary care facility more frequently. The average attendance of patients per day ranges from 1.2 to 6.0 with the average number of patients seen per day about 3.5. These statistics vary with the number of new evaluations compared with the number of follow-up patients seen. Rural clinics tend to have fewer new patients and heavier loads of returning patients.

5-YEAR STUDY OF CLINIC ATTENDANCE PER DAY

	1981	1982	1983	1984	1985
			RURAL*		
Creston	6.4	4.3	5.2	5.1	6.0
Fort Dodge	2.2	--**	2.7	3.5	4.2
Mason City	3.3	3.2	3.0	3.0	3.7
Ottumwa	4.4	4.3	3.8	4.0	4.8
			URBAN		
Davenport	1.6	1.9	2.1	1.7	1.7
Des Moines	1.8	1.4	1.1	1.1	1.2
Sioux City	2.8	2.7	3.2	3.3	3.7
Waterloo	5.6	6.0	5.8	5.8	5.9

*Rural center has no metropolitan area with a population of 50,000. Urban center has at least one metropolitan area with a population of 50,000.

**Fort Dodge clinic was closed during 1982 because of budget cuts.

Until 1982 services were offered by the clinics without charge. As the mandated fee system was implemented the number of patients at all the clinics dropped or the clinic did not have the growth that was anticipated. The effect of the fees was felt for the next one to two years in the clinics even though the charges are modest. None are more than $90.00 and a sliding scale exists for those with low incomes. At the low end of the income scale no cost for the clinic evaluation is assessed. For those people with insurance all or a part of the services are covered (see Appendix-VI for poverty tables).

Clinic Growth

5-YEAR STUDY OF PATIENT ATTENDANCE PER YEAR
AT REPRESENTATIVE CLINICS

	1981	1982	1983	1984	1985
			RURAL*		
Creston	70	51	57	51	60
Fort Dodge	29	--**	57	70	80
Mason City	98	83	69	63	106
Ottumwa	106	104	109	147	181
			URBAN		
Davenport	28	32	34	24	17
Des Moines	92	127	132	134	152
Sioux City	45	32	55	60	77
Waterloo	151	156	146	184	230

*Rural center has no metropolitan area with a population of 50,000. Urban center has at least one metropolitan area with a population of 50,000.

**Fort Dodge clinic was closed during 1982 because of budget cuts.

The number of children receiving services in the regional center clinic programs have increased steadily. The clinics have been very successful and have the support of the public education/special education program, primarily because the clinics provide school personnel direct contact with a physician interested in children with problems which severely affect their educational progress. Other referents find similar advantages in meeting with the physician and evaluation team and being able to discuss freely the medical, health, social and family implications of the problems of these children.

The increasing number of programs provided by the regional centers and especially the IEPC, allows us to make progress toward our goal of providing contemporary health services for children on a regional basis. During the coming decade, the regional centers will become recognized more and more as an effective method of providing on a regional basis many coordinated secondary level child health services for children with complex health, educational and behavioral problems.

The network of the ten regional centers which were in operation throughout the entire Fiscal Year 1985 provided services as follows:

- Number of children/families served in the major programs of the regional center, FY 1985, were IEPC, 903; High Risk Follow-up, 675; ENT, 777; Special Projects, 276 (coronary, speech/language and psychology consultations). Other regional center programs include: scoliosis, hemophilia, lead screening, etc. (see chart before p. 28).

- The regional services result in significant savings in time and costs to the family; $193 is the average cost to families that come to University Hospitals compared to $39 for a CHSC regional center.

- There were 184 claims for children served without charge (under 150% of poverty) or $23,789.21 provided by CHSC. There were 762 claims for children served (above 150% of poverty) or $37,300.57 in recovered costs. (Note: These figures are approximate; some children were seen more than once and the billing cycle and fiscal year are not identical.)

- There were 1,489 families served in "no charge programs" (High Risk Follow-up, Creston ENT, etc., Speech/Language and Psychology consultations).

- In addition, regional staff served at 154 mobile clinics per year at which another 3,841 children received evaluations and planning services.

Center Evaluation

The regional centers and their service programs are evaluated according to an expanded management by objectives plan.

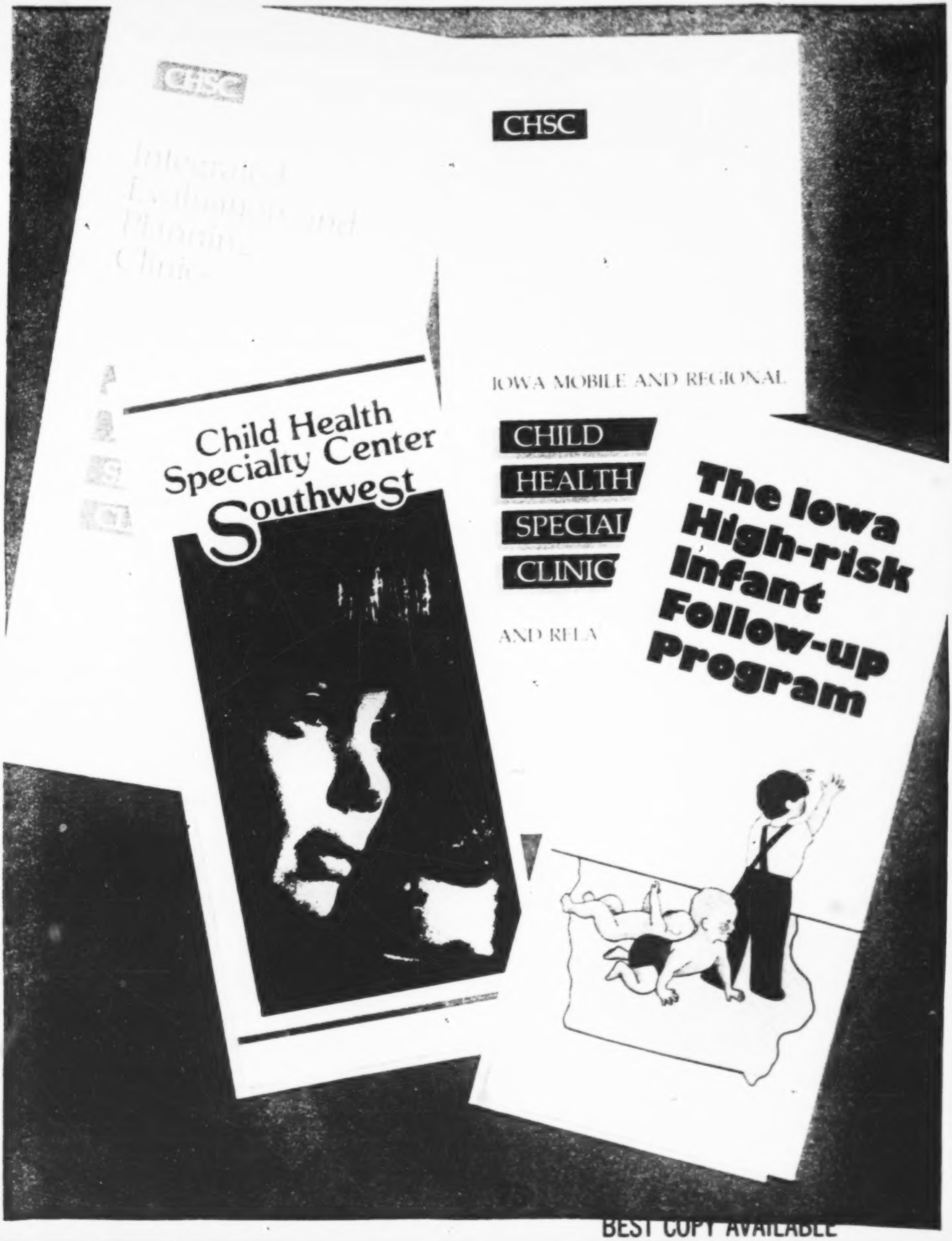
Within two months after the child's evaluation, forms are sent out to each parent and referent requesting their response on a simple set of 7 questions (see Appendix-VII). Favorable response is presently about 96% for parents and 89% for referents.

At the beginning of each fiscal year, regional center staff with advice from their advisory boards are asked to prepare a 10-item list of goals and objectives (see Appendix-VIII) detailing how many clinics they expect to hold, how many patients they expect to evaluate, how many community education programs they expect to conduct, etc. At the close of each year, the centers are thus in a position to evaluate how well they have accomplished the goals and objectives which they themselves have established.

Each center records its nonpatient encounter activities (phone calls, letters, etc.) since many aspects of a successful center can be accomplished without direct patient contact: information and referral, routine inquiries, handling inappropriate referrals, scheduling of appointments, etc.

In narrative form each center reports monthly and yearly on their accomplishments and plans to strengthen their program. Contributing agencies have been asked for their written endorsement of the center and on how well it serves their needs. In conjunction with this, the regional center advisory boards engage in a continual process of center evaluation, considering operational policies, procedures, and long range goals by which the center seeks to serve the children and the families in that particular area of the state. Each center has an annual meeting at the close of the fiscal year when its program is reviewed, annual reports presented, recommendations made, and planning for new activities is undertaken.

VII. Lessons and Conclusions


CHSC
Integrated Evaluation and Planning Clinics
CHSC
IOWA MOBILE AND REGIONAL
CHILD
HEALTH
SPECIAL
CLINIC
AND RELA
Child Health Specialty Center Southwest
The Iowa High-risk Infant Follow-up Program

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Organizational Lessons from Experience

The lessons and conclusions drawn from the programs developed in Iowa through 1977-1986 will have important implications for the years ahead. Our experience shows that in a state with clusters of children in some areas and widely dispersed families in others, children with handicapping conditions and chronic diseases can be provided multidisciplinary evaluations, case management and follow-up services in a cost effective method through integrated coalitions or networking.

At the onset of the program, trained community organizers were employed by CHSC to develop community coalitions of service providers who would form the nucleus of a new service system previously untried on a statewide scale. The following lessons can be extracted from the success of our community-based program during this past decade.

The first lesson was the development of a regional coordinated system of care for children. The task of restructuring state programs each of which has its own legal mandate, various funding sources, administrative structures, rules and regulations would have delayed the implementation of the program for years or may have made it impossible.

Therefore, the Iowa regional center system was developed at the regional level where service is actually provided. Community organizers employed by CHSC cooperated with the regional representatives of state programs who had immediate problems in providing comprehensive services for children. The question, "What does it take to make this area of the state a desirable one in which to raise children and to care for their families?" asked by the CHSC community organizers was the basis for the development of a cooperative program. The solution was a network or coalition of agencies which would undertake a coordinated service delivery approach to these children.

The second lesson was to focus on patient needs. It was recognized that a common population of children existed who required multiple services not available from any single program. Therefore, CHSC made the commitment to contribute a medical team composed of a local pediatrician, a pediatric nurse practitioner and a secretary. The DHS contributed knowledgeable case workers; special education and public health services contributed their staff and support. Hospitals provided office and clinic space. It is important that the program was developed by practicing professionals who were providing direct services for children. The focus always remained on the needs of the children. The centers' core program, the Integrated Evaluation and Planning Clinic, thus bypasses the problems of individual agency organization. Agreements and memoranda of understanding were written after service delivery had begun. This sequence presented clear recognition that patient needs came first and the organizational structure followed.

The third organizational lesson was to focus on cases involving children who needed multiple services from various agencies. This approach had a double advantage. It focused on children who had problems common to many agencies. It also provided an opportunity for the regional agency directors and the medical team work together successfully on a common problem. Thus, the centers are a meeting place where children with multiple problems can be served by a network of representatives of the child caring agencies and programs in the community.

A fourth organizational lesson recognized the importance of community ownership of the center expressed through the formation of a community-based advisory board or child health council. Community ownership is essential if the regional center system is to be successful. As an agency, Child Health Specialty Clinics initiated the center by presenting the concept, employing a community organizer, physician, PNP and secretary. However, responsibility for the operation of the center is under the direction of the community board/council. This board has: (a) policymaking responsibilities for the clinic, (b) serves as a communication forum for agencies and institutions involved with special children; (c) serves as a problem solving body for the center; (d) identifies and moves to fill the needs in the community service system; (e) advocates for special children to various disciplines, professions, and institutions represented in the community as a whole. Mutual goals, agreements and commitments are identified in a Memorandum of Understanding or Interagency Agreement.

Each of these advisory boards and councils also "named" the centers, helping to establish clearly the sense of community ownership. For example one center was named ACES--the Area Comprehensive Evaluation Services. The name expresses clearly the ownership and emphasis which the community-based board intends to see implemented. To further this sense of community ownership, the local PNP and secretary who were employed serve as staff to the board. CHSC, as one of the contributing agencies, is generally represented on the board by the Director of Community Services. Each board elects its own chairperson, establishes its committees, prepares its agendas, and conducts its necessary business.

The fifth organizational lesson recognizes that the centers have been successful because there is "something in it for everyone." There must be a mutual gain which may be intangible but is very important on the organizational level. Thus the fact that no single agency alone can provide comprehensive services for children with special needs is clearly recognized. For example, CHSC can provide medical and health needs but to be successful special education, human and public health services are required. Similarly, special education has the responsibility to provide a variety of educationally related support services, but to do so the establishment of a medical diagnosis may be necessary to complete its educational planning. Frequently, the AEA will also need the services of a public health nurse and case management services from the Department of Human Services.

The sixth organizational lesson is the commitment of Child Health Specialty Clinics to effect change in service delivery through the regional system. In CHSC, the needed leadership commitment was expressed by the Director of Child Health Specialty Clinics in articles and speeches, by the designation of staff, particularly the Director of Community Services to implement the program, and through the use of agency funds necessary to begin the pilot demonstration centers and supplement ongoing federal grants and state support. Without this clear commitment, there would have been little credibility for the program.

Conclusions and Recommendations

On the basis of our decade of experience we have also drawn certain conclusions and recommendations about regional child health centers. First, the child health center concept appeals to state legislators and other regulatory, legislative and funding sources. In fact, the Iowa General Assembly assigned the appropriation and oversight responsibility for the Title V Maternal and Child Health Block Grant programs to the Joint Human Resources Appropriation Subcommittee. In 1982, the Subcommittee charged the State Department of Health, the Iowa Child Health Specialty Clinics, the State Department of Human Services and the University of Iowa Hospitals and Clinics jointly to study and develop recommendations to improve health services for mothers and children through the integration and coordination of programs. These agencies were to study in particular:

1. co-location of services:
2. co-employment of professional staff;
3. reduction of duplication and fragmentation of service;
4. coordination and integration of programs.

Second, an Interagency Agreement/Memorandum of Understanding is needed to identify the commitment of each agency. It states the operational philosophy, mutual expectations and provides a method of resolving operational problems.

Third, there is no uniform guide for states to move toward a coordinated regional system of services. Each state must review its individual health, education and social service state plans in order to meet its individual geographic, political and demographic needs.

The public agencies in each state must work cooperatively to design a community based system for those disabled children who normally require a coordinated evaluation and planning function.

Fourth, there must be a smooth flow of information between the family once all social, medical and educational personnel; responsibility and accountability for providing services must be assigned and accepted.

Fifth, the network approach is the most effective approach for children and their families and for the programs which serve them. Focus on a community based evaluation and planning system for children with chronic or suspected handicapping conditions is essential.

It has been our experience that a voluntary coalition effort by the major state agencies is quite reasonable, it is desired by major state agencies themselves and has the support of the state legislators and the tax paying public. This coalition network approach seems to "make sense." It is our belief that this is the best way to develop an accessible and coordinated program of health, education and social programs for the handicapped, for children with chronic diseases, for their families, and for the professionals who have the privilege of serving them.

VIII. Future Directions, Questions, and Issues

A Parent's Letter

December 4, 1985

Dear

Hi! Randy and I would like to thank you and the wonderful people you work with for all you have done for Justin. We are very happy that he has done so well. I think what you and your staff are doing is great. Keep up the good job. It sure has taken a lot of worries off of us to know that there wasn't anything really wrong with him. You have answered our prayers by taking him to your wonderful people. Thank you very much.

Yours truly

Future Directions for the Regional Child Health Center Network in Iowa

This report so far has described the development and the vast accomplishments in the organization of a network of regional child health centers in the state of Iowa during the decade from 1977 to 1986. The concept for a network of centers had its origin in the belief of John C. MacQueen, M.D., Executive Officer and Medical Director of the Iowa Crippled Children's Program as it was then entitled. At that time, he noted "the nation has no system at the community level to provide the public health services that are unique to children; basic health services; services for chronic diseases and disorders; and health related services." He concluded that "there is therefore a need to create at the community level a service unit that will make basic health services accessible to all children," and he called for the creation of a bold new system in which, "communities will be given the responsibility for determining which child health services are needed and for providing those child health services with state programs serving as a backup resource" and "community programs that provide child health services which will function in close cooperation and collaboration with established community systems (medical care system, educational system, social services system) that provide other child services."

Looking at the years ahead, it must be recognized that the federal/state system of services for children is very different now from that in the mid-1970's. Further, there are practical limits to the gain which can be made solely through community efforts at integration, coordination and networking of services.

In the state of Iowa there has been and will continue to be a need for a centralized state program to organize the provision of complex health services. Needed is a base of integrated services through networking of community resources and tertiary level services.

"What history and practice have taught us is that successful application of regionalization is dependent upon the establishment of a strong community based care system. While a tertiary care center stands at the hub of the system in its research, its exemplary interdisciplinary services in development of care and plans, and its continuing preservice and inservice education, it is ultimately the local physician and the community who use the research, implement the care plans, employ the education in day to day care management and habilitation services and provide appropriate community support services to the family."

The role of the regional center network of Child Health Specialty Clinics is the bridge, an important link between those highly specialized services available in a major medical center and those which can be networked and delivered through regional centers in rural communities.

Particular reference should be given to the development of linkages between primary, secondary and tertiary level of service for children who have such diseases as insulin-dependent diabetes mellitus, hemophilia, and heart disease. The purpose of such linkages is to assure coordination, comprehensive care, and a statewide education program for professionals, related agencies, school personnel and families. Such a program must also provide a central registry for the location of the children, coordination of necessary supplies, and resource information about insurance and rehabilitation.

In Iowa, the regional centers at selected locations have already been involved in providing community based supervision, parent education, guidance and support. The regional PNP/RN staff have held meetings with schools to interpret the needs and the problems of these children and their families. A number of communities have expressed a need for pediatric neurology evaluations that go beyond the evaluations which the integrated clinic itself presently provides and tend to be developmental in focus. In particular,

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McPherson, M.G. Community Based Services for Disabled and Chronically Ill Children and their Families in Developmental Handicaps: Prevention and Treatment, III, American Association of University Affiliated Programs for Persons with Developmental Disabilities; Silver Springs, MD, 1985, p. 46.

many special educators from the Area Education Agencies have felt the need for this type of evaluation to assist them in their educational planning for children with confirmed or suspected seizure disorders. A second major addition to the regional center program involves services to children who are chronically ill and/or are dependent upon modern methods of medical technology for their survival. The building and development of this link between the tertiary level NICUs and PICUs in the state with community based services is and should be one of the major activities for the regional centers in the years to come.

In Iowa, this home- and community-based service program focuses on the role of community coordination and case management as opposed to the direct provision of service. It is our conviction that an excessive burden should not be placed upon parents or siblings in order to meet the home care needs of the technology-assisted and chronically ill child. Long term planning must involve both financial- and community-based case planning services. Planning must occur long before discharge occurs. In order to accomplish this a close coordination with the tertiary level programs must be established. To meet this need, CHSC has employed as a coordinator a PNP who provides this link between the regional staff and the University level tertiary center. Further staff are being added.

Recently agreements have been written with the Department of Human Services for the Title XIX "waiver" children, with Iowa Blue Cross/Blue Shield and with other major insurance carriers. The issue is not what is comprehensive care. This is well known, but the challenge for the remainder of the 20th century is the delivery and financing of it.

A third emerging role is the growing recognition of the changing role of parents in the health care of children with disabilities. Parents are becoming more conscious of their roles and their legal rights in the education of their children. This evolution has led to a greater understanding of the value of parental involvement.

In recent years, the importance of family input in serving chronically ill children has been recognized as a more appropriate and efficient method to achieve the greatest potential for both the child and the family. With the dramatic move toward deinstitutionalization of the 1970's, professionals are now aware that serving the family's needs, not just the child's needs, is of major importance.

In Iowa, a part of the staffing at each integrated clinic is the involvement of the parents in the preparation of the case plan for the child. It is not enough that knowledgeable professionals should prepare the plan as they see best and then deliver it to the parents, but the parents must be active participants in the construction of that case plan, as well as its implementation. Similarly, parents have an involved role in the assessment of their children in the high risk follow-up program. They are vital participants in the home care program for children who are technology dependent or have chronic diseases.

Of significant interest has been the development of the family enrichment weekend. Families with handicapped and developmentally disabled children have many additional stresses and responsibilities compared to other families. These families are in particular need for information about their rights, resources, guardianships, etc., and for networking with other parents. Because of the ever present nature of their child's problems, opportunities for the family to "get away" for conferences and relaxation are exceedingly rare. The goal of the family enrichment weekend is to provide opportunities in a hotel or conference setting for parents to spend time away with their children, time to learn, time to share with other parents, and time for themselves.

In 1984 under the leadership of the Crippled Children's Subcommittee of the Maternal and Child Health Advisory Committee in Iowa, a group of professionals and parents in central Iowa began planning for a family enrichment weekend. A pilot weekend was held February 22, 1985, at the Marriott Hotel in Des Moines and was attended by 23 families and 48 children. A significant result of that weekend was the growth experience of the 100 plus volunteer/sitter companions. These companions not only assisted the parents with their children but they had the opportunity for direct "hands-on" contact with the children in a family oriented setting.

Workshops and seminars were conducted by resource persons for the parents on a wide variety of topics. A highlight of the weekend was the parents' "night out" for dinner together, a social hour and entertainment. Based on the success of that pilot weekend, planning is now underway for the continuation of such weekends in Des Moines and at other locations in Iowa. Funding for the weekend is from a combination of CHSC contributions and those of foundations, civic groups, etc.

Fourth, families are being asked to provide new and crucial methods of care. They are now becoming partners in determining what is best for their child. As they do so, they develop a unique expertise in evaluating their child's growth and development. Further, families need the support that other families who are living in similar situations can provide. The importance of parent-to-parent match-ups for mutual support and encouragement cannot be overestimated.

Therefore, CHSC is also moving quickly to develop regional and community-based parent committees as a part of the Regional Center System which will work closely with a broad range of community agencies to identify a variety of services required by the unique needs of these families, to promote community awareness and to seek for community solutions.

It is anticipated that these committees will be composed of persons who are committed to improving the quality of life for all chronically ill children and their families. While these committee members may belong to active parent support groups, the proposed committees will cross all diagnostic categories and will promote the general services which all families with handicapped and chronically ill children require.

Representative examples of activities which the committees will promote may include, but are not limited to, the following.

1. Respite care.
2. Advocacy.
3. Family enrichment weekend.
4. Communication through parent partnerships.

5. Networking especially with local AEA parent projects.
6. Public relations.
7. Community planning.

A fifth area which will be of major importance in the development and coordination of networks of children's programs in the remaining years of this century involves the utilization of modern computer technology. In the past, many efforts were made to integrate and coordinate public health programs and services. Most of these failed, not because the concept itself was wrong but because it was impossible to share information quickly and effectively. Such sharing must be possible if integration is to occur. In the past it was necessary to use written reports to communicate information which proved to be very inefficient and unsatisfactory. CHSC believes that the answer to the problem of integrating programs and services is new computer technology. CHSC also believes that such technology not only makes integration of services possible, but now obligates us to do so.

As described in this report, CHSC has developed a network of programs for handicapped children which is now tied together by means of a computer information reporting system and links five of the various regional centers with each other and with the CHSC central patient management unit. Further, it is anticipated that as funds permit, the computer pilot project in Ottumwa will be expanded. At present, this pilot project links the Department of Human Services, Child Health Specialty Clinics, and Special Education offices into a network.

Issues and Questions

The Role of the Private Physician in the Child Centers

One of the central ideas is that regional child health centers will provide a place where a private physician with a special interest in developmental pediatrics can practice. The center will provide the support staff and the organization of services. The physician functions as a consultant and does not provide continuing care and treatment. There is no expectation that all the children in the community would be seen in the center.

Who Should Organize Regional Centers

This is an important question and one that must be addressed. Due to the differences in the organization of state governments, it is very likely that there would be no agreement on this question.

The regional child health centers as described in this report are involved with providing health and health-related services. The Crippled Children's Program is designated to be responsible for children who have handicapping conditions or possible handicapping conditions, and follows that it is appropriately assigned the responsibility for developing the regional centers. It is further proposed that the state CC programs should be the convener of those who plan the new system and that they should have a major role in determining the design of the new system. This is a natural role for the CC programs to assume. The state CC programs are the public program with the longest experience in the provision of services for handicapped and chronically ill children; they have experience in conducting a system of services that is a statewide coordinating network of services; they have a very close working relationship with the private medical community; they are responsible for providing services for all handicapped children--their mandate is not limited to just poor children, but to children with handicapping conditions-chronic illness.

However, it is hoped that the regional center program is not looked on as owned by the Crippled Children's Program but instead as a community program monitored by the crippled children's service, a regional center that is mutually used and mutually available to any and all providers of child health services in the community.

The Relationship of the Public School System to the Regional Centers

The center is a referral source for the school system. It should be remembered that the public school system must create an IEP for children who are having difficulty with their educational experience and identified as handicapped. It is an educational plan. The care plan developed in the center is concerned with the child's health and health-related problems. The two plans should not be confused and the health-related plan is not controlled by the requirements that have been established for the development of the IEP. At the end of an IEPC, a written report is developed that includes the findings of the representatives of the various agencies involved in the examination. The conclusion and recommendations of the center plan can and hopefully would be used (with the family's approval) as part of the IEP.

How Can Interagency Coordination be Achieved

Historically, public agencies are not eager to share service activities with other public agencies. There is no doubt about that observation. It could perhaps be said that interagency cooperation will in most cases not occur unless higher administrative policy indicates that cooperation is expected and that the results of the cooperation must be reported. It is true that most state programs would not be interested in cooperation unless it is clearly demonstrated that there was "something in it for them." It is therefore not surprising that the pressure to create coordinated programs will in many cases come from a community, from providers of services in the community and particularly from the family involved. It probably can be said that the degree of cooperation initiated by state agencies will be dependent upon state executive decisions and state legislative charges.

Yet, having said this, it is also our belief that it is the responsibility of each community to help determine the local organization of service programs for children. Therefore, the number and type of health services provided in the regional centers will vary a great deal.

In summary, historically the federal Office of Maternal and Child Health, to a large degree, fueled the momentum for the state CC programs. The state CC programs in turn used the federal guidelines and the federal matching dollars to initiate and support CC programs that served children who live in the communities of the state. In that arrangement, the community, to a large degree, accepted the services that were determined by federal and state initiatives--thus they were, to a large degree, passive partners. The MCH Block Grant legislation of 1981 discontinued these organizational relationships by terminating the federal control of the state CC program and other human services programs. This resulted in considerable confusion because the Block Grant legislation did not create new working organizational relationships between the federal government, state government and the community.

The proposed community-based system described in this report has the potential for creating a balance between federal, state and community control of public programs designed to provide services for children with handicaps or with chronic disease. It has the potential also for creating in communities the capability to determine the services that are needed and to monitor the services provided. This system can also decrease the fragmentation of health services, and creat a system needed to provide comprehensive contemporary health services. It can provide health services that are not available in the private physician's office and the support services needed by this population of mothers and children--support services that are not paid for by Medicaid or private funding arrangements. Finally, it is sufficiently flexible so it can function both in urban and rural areas.

Thus, we are suggesting that the state CC programs encourage the development of a system to provide secondary level services for children with chronic illness and disabling conditions.

This system that proposes revolutionary changes in the state CC programs is made with the full awareness that states vary a great deal in their health system and that any such program would have to be designed to conform to the needs and the health system in each state.

The Iowa statewide system of regional centers does create a balance in the responsibilities of federal, state and community governments in providing for handicapped children.

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X. Appendix

SOUTHEAST AREA
CHILD HEALTH SPECIALTY CENTER

INTER-AGENCY MEMORANDUM OF UNDERSTANDING

This memorandum of understanding is made and entered into this _____ day of ___________, 19_____ by the Iowa Mobile and Regional Child Health Specialty Clinics in Iowa City, IA (CHSC) and the Area Education Agency 16, Burlington, IA the Department of Human Services, District 8, Ottumwa, IA and the Specialized Supplemental Food Program for Women Infant Children (SE IA Community Action WIC Program) Burlington, IA. The general purpose of this understanding is to provide inter-agency coordination of evaluation and planning services for the physically disabled and educationally handicapped children in the Specialized Child Health Center (SCHC) serving Des Moines, Henry, Lee and Louisa counties.

No exchange of funds is required by either CHSC, AEA, DHS, or WIC, no specific payment or receipt of funds is authorized by this agreement and no special budget will be prepared for financial records.

The specific purposes of this agreement are to:

1. Clarify the respective roles of CHSC, AEA, DHS and WIC in meeting the needs of Southeastern Iowa handicapped children with chronic congenital disorders and/or related educational/behavioral problems.

2. Identify the specific responsibilities of each party in meeting these needs.

3. Establish methods for inter-agency cooperation.

A. COMMON ASSUMPTIONS OF THIS UNDERSTANDING

1. Physically disabled and/or educationally handicapped children have all the rights guaranteed by the Constitution and Bill of Rights of the United States. All children and families will be seen on a non-discriminatory basis.

2. The primary function of the SCHC is the provision of a specialized medical assessment and consultation regarding educational, behavioral and social implications. In carrying out the medical assessment and consultation function, SCHC will have the goal of maximizing client participation and involvement of appropriate community agencies in meeting the needs of the client.

3. We mutually agree to the concept of team assessment and consultation for handicapped children and further agree to provide such staff as defined above and as agency resources and obligations permit to serve as members of the team. Planning and follow-up are the responsibilities of the individual agencies, physicians, etc., making the individual referral.

4. An individual case record will be developed for each child seen at the center. This record will include medical, health, educational and social assessments and related recommendations as appropriate. This record and contents will be held in confidence and shall be used and available only to center staff.

5. Confidentiality of the client will be maintained by the SCHC staff through the use of signed release forms as necessary. However, it is understood that the free and unrestrictive flow of client information will be allowed among the appropriate professional staff assigned to SCHC, subject to legal constraints and policies of participating agencies.

6. There will be no charges to the child or family for examinations provided by the assigned or contributed staff to SCHC. However, present CHSC policy seeks to recover the physician charge; third parties are billed first, no charges are made for those under 150% of poverty level, sliding fee scale thereafter, not more than $90 for usual charges for a physician examination. X-rays, labs and supporting examinations are billed to third parties.

B. RESPONSIBILITIES OF SCHC

SCHC is a coalition effort with various state agencies and area organizations to create a secondary level referral center of children and youth with actual or suspected chronic health/medical disorders. Therefore, SCHC will:

1. Facilitate the integration and coordination of services provided by various community agencies.

2. The SCHC core staff and contributed professional staff from the coalition of agencies will provide team medical evaluations and consultations regarding the behavioral, social, educational, nutritional implications of the clients' medical condition. In cases where further psychological, educational, social, nutritional, and/or medical evaluation is needed, referral will be made to the appropriate agencies.

3. Provide copies of all reports of medical and other evaluations to CHSC and other agencies with appropriate releases of information.

4. Provide a comprehensive review of evaluation findings, interpretation and recommendations to the children and families seen at SCHC.

5. Develop an integrated record including the medical findings, conclusions regarding the behavioral, social, educational, nutritional implications and recommendations.

6. Engage in inservice education and training programs throughout the area as professional resources permit.

7. Participate with other agencies and individuals in the planning and development of services for children and youth in the area.

8. Maintain a close relationship with schools, special education, other agencies and referents in order to facilitate integration and continuity of services.

9. The Medical Director of SCHC while maintaining his professional autonomy, will maintain professional/administrative relationship with the CHSC Medical Director.

C. RESPONSIBILITY OF CHSC

1. To pay by contract pediatricians who will serve as medical examiners approximately two days per month in the center at a cost to be mutually agreed upon between the agency and the physician(s). The Medical Director of CHSC will designate a SCHC Medical Director.

2. To provide a pediatric nurse practitioner on agency salary to serve as a nurse coordinator on a half-time basis.

3. To provide a secretary on agency salary to serve as secretary on a half-time basis.

4. To provide laboratory tests and x-rays as ordered by the Medical Director, subject to agency policy for payment.

5. Contribution by the agency for rent of the agency offices is a separate item to be arranged between the agency and the resources available in the area.

6. Services of CHSC regional staff who will serve as the agency's liaison person to SCHC and will provide external support services to enhance the success of the SCHC program.

7. CHSC staff persons are assigned by the agency as a part of the coalition of agencies to the SCHC. While they receive direction from the SCHC Medical Director and Board of Directors, they remain subject to the Board of Regent's Merit System and position description, and are supervised by the agency's Director of Community Services.

D. RESPONSIBILITIES OF AEA 16

1. Provide a liaison person to serve on and meet with the regularly scheduled meetings of the SCHC Board of Directors.

2. Contribute a professionally trained person(s) who will:

    a. Serve as the AEA liaison on the SCHC interdisciplinary staff for the regularly scheduled integrated evaluation clinics.

    b. Facilitate appropriate follow-up services within the AEA system for children seen at the SCHC integrated evaluation and planning clinics.

    c. Assist the specialized child health center core staff in other ways as time and resources permit in order to insure the successful implementation and operation of the child health center program.

3. Facilitate referral for such professional evaluations (example: speech and audiology, psychology, etc.) as may be appropriate.

4. Facilitate, encourage and assist in the identification and the referral of appropriate handicapped children from within the population of children served by AEA 16.

E. RESPONSIBILITIES OF DHS

1. Provide a professionally trained person to serve on and meet with regularly scheduled meetings of the SCHC Board of Directors.

2. Contribute a professionally trained person to provide professional social work services to SCHC:

   a. Provide professional case work services at the regularly scheduled evaluation and planning clinics -- social history, assessment of family functioning, and interpretation of family dynamics. The social worker will also need to have knowledge of child protective services, income maintenance services available through the Department, etc.

   b. Assist with follow-up services which involve DHS and purchases services.

   c. Assist the specialized child health center core staff in other ways as time and resources permit in order to insure the successful implementation and operation of the child health center program.

3. Assist and encourage the identification and referral of qualified handicapped children from within the general population of children served by DHS.

F. RESPONSIBILITIES OF WIC

1. Provide a professionally trained person to serve on and meet with regularly scheduled meetings of the SCHC Board of Directors.

2. Contribute a professionally trained person to provide professional nutritional services to the SCHC:

   a. Provide professional nutritional services at the regularly scheduled evaluation and planning clinics.

   b. Assist with follow-up services which involve WIC and other community resources.

   c. Assist the specialized child health center core staff in other ways as time and resources permit in order to insure the successful implementation and operation of the child health center program.

G. BOARD OF DIRECTORS POLICIES AND RESPONSIBILITIES

The SCHC is a neutral meeting place where the representatives of the various agencies and consumer representatives can work cooperatively to implement mutually agreed upon purposes. The Board includes representatives from these agencies and exists to accomplish these purposes. The Board will make general operating policy decisions and develop its own operations manual. The Board will make decisions about specific operation procedures, forms, where the clinic is to meet, etc. The Board will make decisions about the addition of new projects.

The Board functions as a group to review the progress being made in the development and implementation of the center's programs.

The Board cannot require an agency to exceed its legal mandate. Rather, the Board exists in order to further on a cooperative basis the mandated purposes of the respective agencies in a manner designed to reduce duplication and fragmentation.

When problems are identified, all conflicts will be settled at the lowest level of authority necessary. Failure at this level would necessitate referral to the next higher level of authority in each agency. Failure again to reach a resolution of the problem would involve referral of this matter in a thoroughly documented form to the Directors of the respective agencies.

The Clinic service is under the direction of the Medical Director appointed by CHSC. CHSC, through the Medical Director, assumes the major responsibility for the clinic day and for the professional standards of practice within the clinic of the CHSC assigned staff. AEA, DHS, and WIC assumes responsibility through their designated liaison persons for the maintenance of professional standards of practice for their contributed staff.

H. RELATION OF ASSIGNED AND CONTRIBUTED STAFF TO THE RESPECTIVE AGENCIES

The center is not an autonomous legal entity. All staff assigned by a parent organization remain the employees of their respective agencies. On clinic day these staff are discharging the appropriate responsibilities of their parent agencies in this setting.

Therefore, the liability insurance of the respective agencies continues to be applicable when staff are functioning within the scope of their assigned agency responsibilities.

John C. MacQueen, M.D. Date
Executive Officer and Medical Director
IA Mobile and Regional Child Health
Specialty Clinics; Iowa City, IA 52242

John Bryant, Ph.D. Date
Director, Area Education Agency 16
Burlington, IA 52601

John Owens, District Administrator Date
Department of Human Services
Ottumwa, IA 52501

Christine O'Brien Date
Coordinator
WIC
Burlington, IA 52601

INDIVIDUAL SERVICE PLAN SUMMARY

Child's Name:______________________ I.D.#:__________ Birthdate:____________________

Summary prepared by:________________ Agency:__________ Date:__________ IEPC Clinic:__________

Referrer:____________________ Reason for referral:________________ Clinic date:__________

PROBLEMS - for which service plan is needed. (Diagnosis if descriptive of problems)	FINDINGS - that define or describe problem, e.g., test results. DATE - of findings	SERVICE PLAN - specific to problems. CARE TEAM - identify & agency.	CARE STATUS - at follow-up.* A. Service Received? B. Success of Service DATE - of follow-up.
HEALTH:			
EDUCATIONAL:			
SOCIAL:			
OTHER:			

EXPAND TO SEVERAL SHEETS IF NEEDED,

OR ONE SHEET PER AGENCY.

*A. Service Received:
1. Obtained/completed
2. In progress
3. Not obtained.

B. Success of Service?
1. Goal achieved
2. Progress towards goal

CHILD HEALTH SPECIALTY CLINICS
District XV Specialized Child Health Center, Ottumwa, Ia.

INDIVIDUAL SERVICE PLAN SUMMARY

Child's Name Jarred Birthdate 5/9/77 Clinic Date 7/12/84 Sex M

Summary Prepared by CJones PNP Referent Cathy , Principal Sigourney Elem.

Reason for Referral Difficulties in classroom including trouble sitting still, poor schoolperformance, carelessness and poor concentration

Problems - for which service plan needed, (Diagnosis if descriptive of problems)	FINDINGS - that define or describe problem, e.g. test results DATE - of findings	SERVICE PLAN - specific to problems CARE TEAM - identify & agency	CARE STATUS at followu A)Svc receiv B)Success of Service DATE-of FU
HEALTH: 1. Possible attention deficit disorder	physical exam WNL - some diff. with alternating hand movements	1. Recommended AEA evaluation with special attention to psychological eval. and fine motor evaluation.	
EDUCATIONAL: Currently in a regular classroom with no special help SOCIAL:	Results of Peex done indicate weaknesses in area of visual-fine motor and temporal sequential organization. with marginal perform in some fine motor tasks Marked deterioration of attending skills Needs highly structured classroom situation this Fall plus evaluation by AEA to det. if SE help is needed.		
OTHER: Behavior problems.	See Psych report this date	Recommendations for behavior mod were given by Dr. Disenhouse. RETURN TO CLINIC SEVERAL MONTHS AFTER SCHOOL STARTS FOR FOLLOWUP.	

*A) Service Received?
1. Obtained/completed
2. In progress
3. Not obtained
4. Unavailable

B) Success of Service?
1. Goal achieved
2. Progress towards goal
3. No progress toward goal

HEALTH SURVEY REPORT

This survey was initiated as a result of interest expressed by a number of agencies in the Fort Dodge Area. It was coordinated by the Fort Dodge Specialized Child Service Center, a regional center of the Child Health Specialty Clinics of Iowa City.

A preliminary questionnaire was sent to all of the doctors in the area for their input. Their suggestions were incorporated into the final survey instrument which was distributed through the schools in Webster and surrounding counties. The largest and smallest school districts and one parochial school in the nine counties were asked to send the questionnaires home with one section of their kindergarten class. Of the 21 districts asked, 16 agreed to participate and the Arrowhead AEA distributed the material to the schools. Completed forms were received back from 15 schools. The survey instrument is shown as Exhibit A at the close of this report. Exhibit B is the parent' cover letter.

RESPONDENTS

One hundred forty-five families with two hundred eighty-seven children returned the survey form. Sixty-nine percent of the responses were from Buena Vista, Calhoun, and Greene Counties and the remaining responses were from Hamilton, Pocahontas, Sac and Webster Counties. They were considered to be from the county of their school district. There were eighty-eight children under age five. One hundred fifty-two children were between the ages of six and ten with thirty-seven in the eleven to fifteen age range. Ten were sixteen or over.

DOCTOR VISITS

The families with older children went to the doctor less frequently. Of the twenty-five percent who said they went to the doctor more often than every six months, several said, "with the baby only." Forty-three percent said they go yearly and twenty-three percent said it is every two years. Nine percent said it is more than two years between doctor visits for their children.

COST FACTOR

Sixty percent of the families indicated that the cost of paying for adequate medical services was no problem and four percent did not state either way. Thirty-six percent felt that cost was a problem. Of those for whom cost was a problem, five families from five different counties were using Title XIX. No families were using the medically needy program.

IF I COULD AFFORD IT

Finances seemed to be a factor in some services. Families were asked to complete the following statement, "If I could afford to pay for them, my child would have the following medical services:. . ." The response by ten percent of the families was, "yearly physicals," and others said more thorough or more frequent physicals.

Eight percent said, "dental checkups," and three percent said, "vision checks." Others said they would take their children to specialists. Specific services mentioned were: tonsillectomy (2), tubes in ears, glasses, allergy tests, booster shots, facial birthmark removal, psychological help, and private speech therapy.

Some families said they would purchase more insurance.

INSURANCE

Eighty-three percent of the families had some medical insurance. For many it was only hospitalization and fifty-six percent of the policies had large deductibles and/or many exclusions. Some coverage for office visits was included in fifty-six percent of the policies and sixty percent provided some coverage for medications. In Buena Vista and Hamilton Counties, there were no families without some type of medical insurance coverage.

WELL CHILD CLINICS

Twenty percent of the families indicated that they presently use a well child clinic for checkups and/or immunizations. An additional forty-eight percent indicated they would use well child clinics if they were available in their community. Some indicated they were not sure what a well child clinic was.

MEDICAL SERVICE AVAILABLE

The responses to this question indicated some confusion as to the definitions of well child clinic and some specialty areas.

SERVICE BY MULTIPLE AGENCIES

Thirteen percent of the families indicated that their children are currently receiving service from two or more agencies.

WHERE TO GO FOR HELP

The questionnaire asked where the family would go for help if their resources should be exhausted. Seventy-seven families did not give an answer and seventeen indicated that they did not know. Six said they would go to their banker or credit union.

The Department of Human Services or Title XIX was given by ten families while state papers to Iowa City and WIC Clinics were each listed twice. Two respondents said they would contact the public health nursing agency. Other responses were each mentioned once. They were, local outreach office, Social Security, local clinic, state agencies, and Hill Burton. One family said they would not accept help and others indicated that they had not experienced the problem yet and therefore had had no reason to study what help was available.

WORKSHOPS

Seventy-one percent of the respondents indicated a willingness to attend classes or workshops if they were available in their community and if babysitting was provided. From Calhoun County, respondents indicated that such workshops are available from their Extension Service and through the Wellness Department of the hospital.

The percentages who indicated interest in each workshop were as follows: nutrition, 26%; weight loss, 39%; parenting, 49%; and stress management, 45%. Interest did not appear to be related to the distance from medical services. See chart on Exhibit C.

The question was asked as to the interest of children in attending teenage workshops. The survey was only distributed to parents of kindergarten students therefore there were not enough teenagers to make predictions.

CHRONIC HEALTH PROBLEMS

One third of the families reported that their children had some type of chronic health problem. The most frequently mentioned were allergies, asthma, and ear problems.

Twelve families reported ear problems with three others reporting a hearing loss. Nine familes had allergy problems and another ten said their children had asthma.

Other chronic problems listed included bronchitis (2), heart murmur (2), tonsillitis (2), orthopedic disorder, headaches, eczema, urinary tract infections, seizures, diabetes, and a hereditary dental problem (no tooth enamel). One child had Down syndrome and one had had a brain tumor removed.

NEEDED SERVICES

Families were given the opportunity to say what kind of medical service they would like to have for their community. From those who had a physician, seventeen indicated that they would like a pediatrician.

Families who lived at least seven miles from any medical services were more basic in their requests with one requesting a physician's assistant and fourteen requesting a family physician. Five indicated emergency help including good equipment for their rescue unit, EMT's, paramedics, an ambulance, and persons certified for CPR. Nine indicated that they would like immunization or well child clinics.

Twenty-three persons living near a hospital were more interested in adding specialists. Those specifically listed were obstetrician, gynecologist (2), pediatric orthopedist (2), allergist (5), ophthalmologist, ear, nose and throat (8), oncologist (1), and a cardiologist (2). Others mentioned included a dentist (3), orthodontist, pharmacist, mental health counselor, and a physician using totally natural methods.

Only two families expressed a desire for another doctor so there could be a choice. Five families from Calhoun County especially commended their local medical service.

CONCLUSIONS

Responses indicate that most acute medical needs are being met but that routine screenings are done less freqiently when financial constraints are present.

Respondents apparently have little knowledge of resources available for medical help when there is a financial problem.

RECOMMENDATIONS

There needs to be some public information activities to better inform the public as to resources available for assistance with medical care.

Health workshops and/or classes in nutrition, weight loss, stress management, and parenting need to be made available in small towns and in county population centers.

Any survey involving the schools should be done earier in the year to avoid end-of-year school activities. Perhaps surveys need to be personally picked-up from each school.

Terms, such as well child clinic and service agencies, need to be defined.

EXHIBIT A

COUNTY ____________________

HEALTH QUESTIONNAIRE

1. My children are the following ages: ____0-5 ____6-10 ____11-15 ____over 15 yrs.
2. The time between doctor's office visits for my children is: ____more than 24 months ____13-24 months ____6-12 months ____1-5 months.
3. I use a Well-Child Clinic for screening and/or immunizations. ____Yes ____No
4. I would use a Well-Child Clinic if one were available in my county. ____Yes ____No
5. My child/children receive help from more than one agency. ____Yes ____No
6. My child/children have the following chronic health problems:____________________
____
7. My family travels the following distance to get medical care:
____0-5 miles ____6-25 miles ____26-50 miles ____over 50 miles.
8. Paying for adequate health services is a problem for my family. ____Yes ____No
9. I use the following pay for health care: ____private insurance ____Title XIX ____medically needy progaram ____personal resources. (Mark as many as apply)
10. The private insurance coverage for my children includes: ____hospitalization ____office visits ____medications ____large deductible ____many exclusions
11. When my resources are exhausted I would go to the following agency for assistance:
____
12. If I could afford to pay for them, my child would have the following medical services:
____
13. The following medical services are available for children in my town:
    - ____immunization clinic
    - ____well-child clinic
    - ____public health nurse
    - ____family physician
    - ____hospital
    - ____pediatrician
    - ____allergist
    - ____ear, nose, throat specialist
    - ____child bone specialist
    - ____child heart specialist
14. The nearest emergency room is ____miles from my home.
15. If we could have more medical services in my town, I feel that the following would be the most important:____
16. I would probably attend the following classes or workshops if they were in my town:
____nutrition ____weight loss ____parenting ____stress management
17. My teenager would probably attend the following classes for teenagers:
____nutrition ____weight loss ____parenting ____stress management

PLEASE RETURN THIS QUESTIONNAIRE TO YOUR CHILD'S TEACHER BY
MAY 16!

Sf:09/11/86mm

EXHIBIT B

May 8, 1986

Dear Parent

We need your help! Can you help us determine the need for medical services in your town?

There is concern that in "tough" times families may not be able to travel long distances to obtain medical help or may not be able to purchase services that are available.

Recently a group of community persons representing a variety of agencies met to discuss medical needs of the area especially for children. As a result of this discussion, it was decided that the persons to ask were the parents. Therefore we are contacting parents of kindergarten children in different school districsts to ask for their help in completing the questionnaire.

Confidentiality - You do not need to sign your name on the form. We are trying to get general information for your county and the area and do not need to identify persons. All information received will be sent to our Center in Fort Dodge and will be compiled there as it relates to the nine-county area and for each county or two-county area.

Workshops/classes - If there is enough interest in a particular workshop or class, we will try to get something started and we will publicize it in the local news media.

We appreciate your taking the time to help with this. Please feel free to write additional comments on the back of the form. Return the form to your child's teacher by May 16.

We would also like to thank your school for serving as a collection point to make it easier to return the forms. If you prefer you may mail your completed form to the above address.

Sincerely

Kieran Einwalter, C.P.N.P.
Medical Coordinator

EXHIBIT C

WORKSHOP RESPONSE

The number before the slash represents interested respondents.

The number following the slash is the total number of respondents.

	Nutrition	Weight Loss	Parenting	Stress
Buena Vista	8/34	11/34	16/34	14/34
Calhoun	4/29	9/29	11/29	12/29
Greene	6/24	12/24	15/24	11/24
Hamilton	4/11	7/11	5/11	4/11
Pocahontas	2/8	3/8	2/8	1/8
Sac	9/30	12/30	18/30	20/30
Webster	5/10	3/10	5/10	3/10
AREA 5	38/145	57/145	72/145	65/145
Percent Interest	26%	39%	49%	45%

1:6

FY' 87 CHSC SLIDING FEE SCALE
Based on Adjusted Gross Income
Effective 7/1/86

Size of Family Unit/Charge %	A (150% poverty) *000%	B (200%) 025%	C (250%) 050%	D (300%) 075%	E 100%
1	less than 8,040	up to 10,720	up to 13,400	up to 16,080	greater than 16,080
2	10,860	14,480	18,100	21,720	21,720
3	13,680	18,240	22,800	27,360	27,360
4	16,500	22,000	27,500	33,000	33,000
5	19,320	25,760	32,200	38,640	38,640
6	22,140	29,520	36,900	44,280	44,280
7	24,960	33,280	41,600	49,920	49,920
8	27,780	37,040	46,300	55,560	55,560
9	30,600	40,800	51,000	61,200	61,200
10	33,420	44,560	55,700	66,840	66,840
11	36,240	48,320	60,400	72,480	72,480
12	39,060	52,080	65,100	78,120	78,120
+ per additional family member	2,820	3,760	4,700	5,640	5,640

*MEDICAID patients will always be Code 000%.

Data Systems
5-6-86

April 14, 1986

TO: CHSC Staff

FROM: Dr. John MacQueen

SUBJECT: CHSC Physician Procedures and Charges

For consistency and accountability, Child Health Specialty Clinics will adjust its physician service procedures and definitions to remain compatible with University Hospitals. CHSC will continue to emphasize consultation services on initial visits and label return visits to the same clinic as office services.

The CHSC will, effective with April 15, 1986 services, describe first visits to a particular type of clinic as initial consultation services with subsequent recall visits to the same clinic described as follow-up office services.

The level of services provided at each visit will continue to be indicated by the examiner with appropriate procedure costs selected by the person preparing the bill.

Procedure codes and charges for initial consultation services are (new to clinic) as follows:

90600	Limited -- $30
90605	Intermediate -- $60
90610	Extensive -- $90
*90620	Comprehensive -- $120

Procedure codes for follow-up office services (same clinic) are as follows:

*90040	Brief -- $15
90050	Limited -- $30
90060	Intermediate -- $60
90070	Extensive -- $90

Each procedure will follow definitions listed in AMA-CPT IV with agency examples for additional clarification as necessary. A limited service is usual for orthopedics and otolaryngology; an intermediate service is usual for cardiology and muscle; an extensive service is usual for cystic fibrosis, IEPC and pediatric developmental.

*A comprehensive exam is the exception on a new patient and a brief exam is the exception on a recall patient.

WATERLOO

October 1, 1985 - September, 1986

County of Residence	IEPC	Risk Assess.
Benton	2	0
Black Hawk	155	63
Bremer	16	4
Buchanan	11	3
Butler	7	6
Chickasaw	1	5
Delaware	2	2
Fayette	2	2
Grundy	8	1
Hancock	1	0
Plymouth	0	1
Tama	2	0
Out of State	1	0
Totals	208	87

WATERLOO

October 1, 1985 - September 30, 1986

	IEPC		Risk Assess.	
No. Clinic Days	36		41	
No. Patient Visits	208		87	
No. New Patients	154	74.0%	59	67.8%
Ave. Attendance/Clinic	5.8		2.1	
AGE				
Under 1 year	4	1.9%	62	71.3%
1- 4	49	23.6	25	28.7
5-11	123	59.1	0	0
12-14	23	11.1	0	0
15-18	9	4.3	0	0
19 and over	0	0	0	0
SEX				
Male	161	77.4%	44	50.6%
Female	47	22.6	43	49.4
ETHNICITY				
White	197	94.7%	80	92.0%
Asian	1	0.5	0	0
Black	10	4.8	7	8.0
FAMILY CHARGE %				
0%	123	visits		59.1%
25	23	"		11.1%
50	20	"		9.6%
75	11	"		5.3%
100	30	"		14.1"
Other	1	"		0 %

Waterloo
October 1, 1985 - September 30, 1986

SOURCE OF REFERRALS

County	Phys/Clin	PHN & Sch Nurses	AEA	Parent	Other	Totals
Black Hawk	47	22	81	0	9	159
Bremer	2	0	0	0	0	2
Buchanan	0	0	3	0	0	3
Grundy	2	0	1	0	0	3
Totals	51 30.5%	22 13.2%	85 50.9%	0 0.0%	9 5.4%	167

REFERRAL PROBLEMS

Code	Problem	#
3153	Speech and/or Language Disorder	5
3159	Developmental Delay	3
3154	Motor Skill Delay	22
3094	Family Problems &/or Parenting	1
3140	Attention Deficit &/or Hyperactivity	68
3093	Behavior Problems	31
3152	Learning Difficulties	8
3150	Learning Disability	1
3076	Enuresis	2
3459	Convulsive Disorder	17
7834	Short Stature &/or Failure to Thrive	1
7849	Other ENT	2
7839	Other Nutrition, Metabolism, Endocrine	2
7819	Other Neuromusculoskeletal	2
7852	Other Cardiovascular	1
7809	Other Mental &/or Behavioral	1
Totals		167

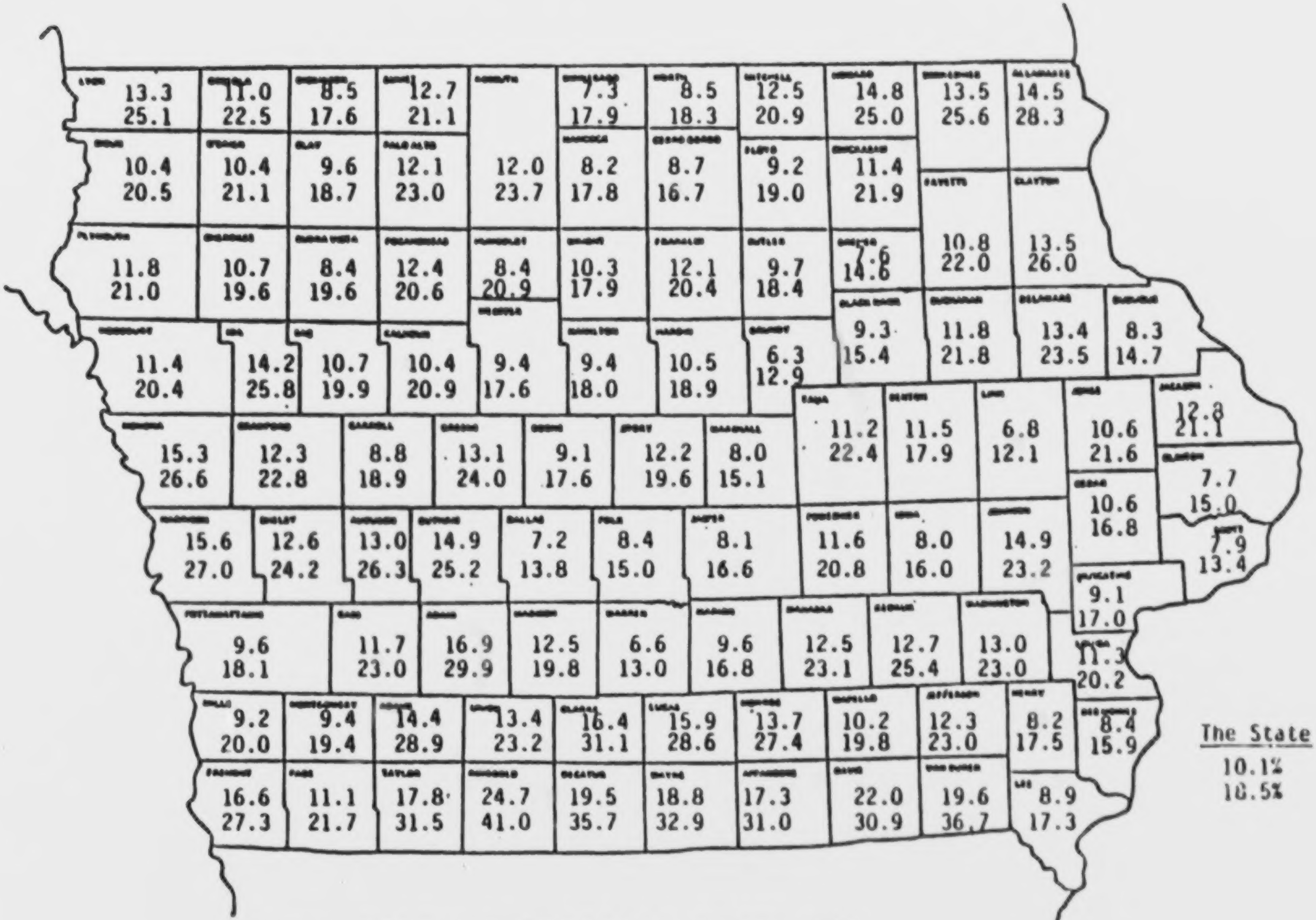
Waterloo
October 1, 1985 - September 30, 1986
IEPC Clinics

Total Diagnoses	299
CARDIOVASCULAR	6
Functional heart murmur	5
Enlargement of lymph nodes	1
ENT & HEARING	3
Congenital malformation of ear	1
Otitis media and/or mastoiditis	1
Hearing deficit	1
SPEECH	9
Articulation including delayed speech	7
Organic speech disturbance	2
RETARDATION & DEVELOPMENTAL	33
Down syndrome	1
Mental retardation	1
Developmental retardation	24
Physical retardation	7
BEHAVIORAL	159
Personality disorder	1
Learning problem	5
Transient situational personality disorder	6
Enuresis	2
Hyperactivity	53
Attention deficit disorder without hyperactivity	33
Behavior problem	51
Other mental, psychoneurotic & personality disorders	8
ORTHOPEDIC	9
Congenital hip dislocation	1
Tibial torsion	1
Metatarsus adductus	1
Pectus excavatum	1
Diseases of musculoskeletal system	4
Abnormality of gait	1
NEURAL & NEUROMUSCULAR	50
Cerebral palsy	3
Convulsive disorder	29
Infantile & febrile convulsions	3
Microcephalus	1
Reduction deformity of brain	1
Other neuromuscular disorders	8
Lack of coordination	5

Waterloo
October 1, 1985 - September 30, 1986
IEPC Clinics, continued

RESPIRATORY	5
Asthma & allergy	1
Other respiratory disease	2
Other symptoms such as breath-holding spells	2
ENDOCRINE, METABOLIC, NUTRITIONAL	2
Obesity	2
EYE	5
Disorders of refraction & accommodation	1
Strabismus	2
Other eye	2
EARLY INFANCY	1
Fetal alcohol syndrome	1
GENITOURINARY	0
HEMATOLOGICAL & NEOPLASMS	0
GASTROINTESTINAL	5
Digestive system disease	3
Nausea & vomiting	2
SKIN	0
RHEUMATOID ARTHRITIS & COLLAGEN VASCULAR	1
Juvenile rheumatoid arthritis	1
CONGENITAL MALFORATIONS NEC	1
Multiple system syndrome	1
OTHER CONDITIONS NEC	10
Toxic effect of lead	3
Abnormal posture or headache	5
Deferred	2

PERCENT OF PERSONS BELOW POVERTY LEVEL
PERCENT OF PERSONS BELOW 150% OF POVERTY LEVEL


13.3 25.1
11.0 22.5
8.5 17.6
12.7 21.1
7.3 17.9
8.5 18.3
12.5 20.9
14.8 25.0
13.5 25.6
14.5 28.3
10.4 20.5
10.4 21.1
9.6 18.7
12.1 23.0
12.0 23.7
8.2 17.8
8.7 16.7
9.2 19.0
11.4 21.9
10.8 22.0
13.5 26.0
11.8 21.0
10.7 19.6
8.4 19.6
12.4 20.6
8.4 20.9
10.3 17.9
12.1 20.4
9.7 18.4
7.6 14.6
11.4 20.4
14.2 25.8
10.7 19.9
10.4 20.9
9.4 17.6
9.4 18.0
10.5 18.9
6.3 12.9
9.3 15.4
11.8 21.8
13.4 23.5
8.3 14.7
15.3 26.6
12.3 22.8
8.8 18.9
13.1 24.0
9.1 17.6
12.2 19.6
8.0 15.1
11.2 22.4
11.5 17.9
6.8 12.1
10.6 21.6
12.8 21.1
15.6 27.0
12.6 24.2
13.0 26.3
14.9 25.2
7.2 13.8
8.4 15.0
8.1 16.6
11.6 20.8
8.0 16.0
14.9 23.2
10.6 16.8
7.7 15.0
7.9 13.4
9.6 18.1
11.7 23.0
16.9 29.9
12.5 19.8
6.6 13.0
9.6 16.8
12.5 23.1
12.7 25.4
13.0 23.0
9.1 17.0
11.3 20.2
9.2 20.0
9.4 19.4
14.4 28.9
13.4 23.2
16.4 31.1
15.9 28.6
13.7 27.4
10.2 19.8
12.3 23.0
8.2 17.5
8.4 15.9
16.6 27.3
11.1 21.7
17.8 31.5
24.7 41.0
19.5 35.7
18.8 32.9
17.3 31.0
22.0 30.9
19.6 36.7
8.9 17.3
The State
10.1%
18.5%

Source: 1980 Census, PHC 80-S2-17, January, 1983
Advanced Estimates of Social, Economic, and Housing Characteristics
Table P-4

SPECIALIZED CHILD HEALTH SERVICES --- Referrer Questionnaire

Instructions: Check the blanks below to tell us whether or not you were satisfied with the services. Please provide comments to explain your answers.

1. Were the clinic services provided at a time appropriate to your needs and those of the child?

   ___ Yes ___ No

   Comment:

2. Were your questions regarding the child answered by the clinic report and/or conference?

   ___ Yes ___ No

   Comment:

3. Did the clinic evaluation and/or conference result in a change in the service plans for the child?

   ___ Yes ___ No ___ No service plan is needed.

   Comment:

4. Has there been improvement in the child's problem(s)?

   ___ Yes ___ No ___ There's no problem. ___ Improvement is not expected.

   Comment:

Please turn the page over and complete the questions on the back.

5. What was the most useful outcome of the clinic evaluation and report from your point of view?

6. Comment on anything you are concerned about or pleased about.

If you prefer to answer the questionnaire without identifying yourself, trim the name off the sheet. Then return the form to us in the enclosed stamped envelope.

Thank you.

Date ______ Signature ______

SPECIALIZED CHILD HEALTH SERVICES --- Parent/Guardian Questionnaire

Instructions: Check the blanks below to tell us whether or not you were satisfied with the services. Please provide comments to explain your answers.

1. Were clinic services provided at a time and place appropriate to your needs and those of your child?

   ___ Yes, I was satisfied. ___ No, I was not satisfied.

   Comments:

2. Was the reason for the clinic visit clear to you at the time the visit was scheduled?

   ___ Yes, the reason was clear. ___ No, the reason was not clear.

   Comments:

3. Did the clinic visit help you understand your child problem(s)?

   ___ Yes, I understand. ___ I understood the problem(s) before the visit.

   ___ No, I do not understand as well as I would like.

   Comments:

4. Was there a change in the treatment or service program for your child following clinic?

   ___ Yes, there was a change. ___ No, there was no change.

   ___ No treatment or service is needed.

   Comments:

Please turn the page over and complete the questions on the back.

5. Are you having any difficulty getting the care that is needed for your child?

___ Yes, I am having difficulty. ___ No, I am having no difficulty.

___ No care is needed.

Comments:

6. Has there been improvement in your child's problem(s)?

___ Yes, there has been improvement. ___ There is no problem.

___ Improvement is not expected. ___ No, there has not been improvement.

Comments:

7. Comment on anything you are concerned about or pleased about.

If you prefer to answer the questionnaire without identifying yourself, trim the name off the sheet. Then return the form to us in the enclosed stamped envelope.

Thank you.

Date ____________ Signature ______________________________

SPECIALIZED CHILD HEALTH SERVICES --- Patient Questionnaire

Instructions: Check the blanks below to tell us whether or not you were satisfied with the services. Please provide comments to explain your answers.

1. Were clinic services provided at a time and place appropriate to your needs?

   ___ Yes, I was satisfied. ___ No, I was not satisfied.

   Comments:

2. Was the reason for the clinic visit clear to you at the time the visit was scheduled?

   ___ Yes, the reason was clear. ___ No, the reason was not clear.

   Comments:

3. Did the clinic visit help you understand your problem(s)?

   ___ Yes, I understood. ___ I understood the problem(s) before the visit.

   ___ No, I do not understand as well as I would like.

   Comments:

4. Was there a change in the treatment or service program for you following clinic?

   ___ Yes, there was a change. ___ No, there was no change.
   ___ No treatment or service is needed.

   Comments:

Please turn the page over and complete the questions on the back.

5. Are you having any difficulty getting the care that you need?

___ Yes, I am having difficulty. ___ No, I am having no difficulty.

___ No care is needed.

Comments:

6. Has there been improvement in your problem(s)?

___ Yes, there has been improvement. ___ There is no problem.

___ Improvement is not expected. ___ No, there has not been improvement.

Comments:

7. Comment on anything you are concerned about or pleased about.

If you prefer to answer the questionnaire without identifying yourself, trim the name off the sheet. Then return the form to us in the enclosed stamped envelope.

Thank you.

______________ ______________________________

Date Signature

MEDICAL EVALUATION CLINIC FOR CHILDREN OF AREA II - Parent/ Guardian Questionnaire SUMMARY

MASON CITY July - December 1984 Response: 18/27 66.7%

Instructions: Check the blanks below to tell us whether you were or were not satisfied with the services. Please provide comments to explain your answers.

1. Were clinic services provided at a time and place appropriate to your needs and those of your child?

   Yes: 16 89% No: 2 11%

   8 comments. Half the parents commenting were pleased with the availability of the clinic or the effort made to set up appointment times convenient for the family. One working parent said he/she was unable to attend the evaluations of two children because their appointments were mid-afternoon. There was a late cancellation for another family because the physician became ill. Another mentioned the distance to clinic.

2. Was the reason for the clinic visit clear to you at the time the visit was scheduled?

   Yes: 16 89% No: 2 11%

   2 comments. One said the reason for the visit and what to expect at the clinic was very clearly explained to them. The other said, "I still don't know exactly why."

3. Did the clinic visit help you to understand your child's problem(s)?

   Yes: 9 50% I understood before the visit: 8 44% No: 1 6%

   7 comments. Four felt the clinic visit increased their understanding. In some cases, it ruled out a physical problem. In one, the parents felt better "able to cope with what might happen." Two explained the understanding of the problem they had before the visit and another added that "I don't know really any more than I did before."

4. Was there a change in the treatment or service program for your child following clinic?

   Yes: 11 61% No: 5 28% No treatment or service needed? 2 11%

   6 comments. Five reported changes in treatment (medication; surgery) or programs (counseling; AEA; DHS). One said the recommendation was to continue as before.

5. Are you having any difficulty getting the care that is needed for your child?

   Yes: 1 6% No: 13 72% No care needed: 3 16% Blank: 1 6%

   3 comments. Two said they are pleased with the care or help to get the care that they are presently receiving. Another said no care is needed but when there are questions he/she can call and get immediate answers.

6. Has there been improvement in your child's problem(s)?

   Yes: 12 66% There is no problem: 1 6% Improvement not expected: 0 0% No: 4 22% Blank: 1 6%

   9 comments. Five parents were very pleased with and noted the improvement in or resolution of the problem. One of them said the child was "just like a new child." Another felt the special preschool recommended wouldn't be needed because of the child's progress. Three reported little or no improvement and residential treatment was later recommended for one child.

7. Comment on anything you are concerned about or pleased about.

   8 comments. Parents were appreciative of the clinic services available to them and their children. The clinic staff was noted to be "the greatest," concerned and willing to help.

   Three parents expressed concerns--no improvement in problem; a new problem that needs to be evaluated; question about discontinuing medication for the summer.

MEDICAL EVALUATION CLINIC FOR CHILDREN OF AREA II - Referrer Questionnaire SUMMARY

MASON CITY July - December 1984 Response: 17/21 81.0%

Instructions: Check the blanks below to tell us whether you were or were not satisfied with the services. Please provide comments to explain your answers.

1. Were the clinic services provided at a time appropriate to your needs and those of the child?

   Yes: 17 100% No: 0 0%

   5 comments. Comments, in general, were positive. One noted the convenience of a late afternoon appointment for a working mother. Two commented that the families had many needs.

2. Were your questions regarding the child answered by the clinic report and/or conference?

   Yes: 14 82% No: 1 6% Some: 1 6% Blank: 1 6%

   6 comments. Although many questions were addressed and some answered, answers were not found in all cases, according to most of those who commented.

3. Did the clinic evaluation and/or conference result in a change in the service plans for the child?

   Yes: 4 23% No: 10 59% No service plan is needed: 3 18%

   11 comments. Three commented on changes (medication started; medication given consistently; behavior modification tried). No changes were reported in eight cases. The clinic recommendations reinforced existing service plans for four children. Two children improved and didn't need a change.

4. Has there been improvement in the child's problem(s)?

   Yes: 7 41% No: 5 29% There's no problem: 0 0%

   Improvement is not expected: 1 6% Yes & No: 1 6% Blank: 3 18%

   15 comments. Eight commented on some degree of improvement ranging from "somewhat" to "fantastic." In one of these cases, there was dramatic improvement while on medication but deterioration when medication was given irregularly. One referrer reported inconsistent signs or progress. Six said there was no improvement but two of them were optimistic that improvement would occur.

5. What was the most useful outcome of the clinic evaluation and report from your point of view?

14 comments. Useful outcomes noted included: ruled out a medical basis for problems (4); diagnosis (2); recommendations for treatment (4); second opinion (2); improvement in problems (3); reassurance.

6. Comment on anything you are concerned about or pleased about.

9 comments. Four referrers expressed concern about problems in the patient's family, continuation of the patient's problem, or medication management. One referrer did not receive a copy of the report and another felt more explanation of the symptoms mentioned in the report was needed.

Three referrers were pleased with: the availability of clinic services for patients who otherwise might not seek follow-up services; the thorough exam "done in a gentle professional manner;" improvement in the child's problems.

Regional Child Health Centers
Monthly Report - Objectives/Accomplishments

CENTER: ______________________ DATE: ______________________

Person Responsible	Projections Regional Child Health Center Activities	Accomplishments

FY 1987

Month | Year to Date

1. ______ IEPCs will be conducted to provide multidisciplinary team assessments.

2. ______ children will receive multidisciplinary team assessments and the appropriate patient reports submitted.

3. Special clinics to be held:

   ______ High Risk Followup; ______ patients
   ______________________; ______ patients
   ______________________; ______ patients

4. ______ Regional Center Advisory Board meetings will be held.

5. ______ contacts will be made to referent agencies to explain and interpret the center program, goals, and operation.

6. ______ community education programs will be conducted to maintain or increase the level of professional practice in the area.

7. Direct patient contacts (other than at clinic).

8. Indirect patient contacts (phone/letter).

9. Site visits made to review operations and implementation of CHSC objectives and programs.

10. Other center activities (home care, scoliosis, etc.).

O V E R

MONTHLY REPORTING ON ACTIVITIES & FUNCTIONS OF THE COORDINATOR/SECRETARY

A. Goals and Objectives -- reverse side.

B. Narrative report on: (1) IEPC, etc. -- patient care functions;
(2) CHSC -- inservice training and community education;
and, (3) CHSC Board -- concerns, problems and activities.
(4) Etc.